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A psychooncology intervention for newly diagnosed cancer patients in a hospital outpatient clinic

Wells, Michael E., Ph.D.

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U·M·I
300 N. Zeeb Rd.
Ann Arbor, MI 48106

A PSYCHOONCOLOGY INTERVENTION FOR NEWLY DIAGNOSED CANCER PATIENTS IN A HOSPITAL OUTPATIENT CLINIC

by

Michael E. Wells

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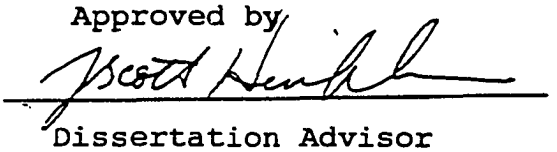

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This dissertation has been approved by the following committee of the Faculty of the Graduate School of the University of North Carolina at Greensboro

Dissertation Adviser _____

Committee Members _____

_____

_____

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The purpose of this study was to reduce anxiety and distress of newly diagnosed cancer patients with a brief, one-time orientation program at an outpatient Hemotology/Oncology clinic. Patients were randomly assigned to intervention and control groups. The intervention group received a preparatory/ orientation presentation which consisted of a clinic tour, general information (a summary of clinic procedures, various roles of the medical team, and facts about the psychosocial support service), and the opportunity for a question and answer period with a counselor experienced in oncology services. Situational anxiety (state-anxiety) and distress were not significantly different for the two groups when measured at the initial clinic visit. However, both situational anxiety and distress significantly decreased for patients in the treatment group after 7 to 14 days and increased for patients in the control group after the same period of time. There was a demonstration of gained knowledge regarding cancer clinic functioning and available psychosocial supports. Significant others in the patients' lives confirmed the follow-up findings of differences in anxiety and distress between control

and treatment groups. These data indicated that the preparatory/ orientation presentation was instrumental in reducing situtational anxiety and distress associated with a recent diagnosis of cancer and can be delivered within the context of a outpatient Hemotology/ Oncology clinic.

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CHAPTER I

Introduction

Cancer is a large group of more than 100 separate diseases, characterized by the uncontrolled spread of abnormal cells in the human body. It is predicted that more than 75 million (about 30% of the population) people in the United States will have cancer some time in their lives. Three out of four families will be affected by the illness (American Cancer Society, 1990). The economic cost of cancer for 1991 was estimated at $83 billion (Broder, 1990), but this figure is small in comparison to the human cost of this disease. These cumulative costs make the physical disease of cancer a major national health care challenge. One million Americans will learn this year that they have cancer and about one-half of them will eventually die of their disease (Boring, Squires, & Tong, 1991).

According to the latest figures available (1987), cancer resulted in 476,927 deaths (254,653 males; 222,274 females), was the second leading cause of death in the United States, and accounted for nearly one quarter (22.5%) of all deaths. Cancer was the first or second leading cause of death in 1987 for both genders at all age groups (1-14 years, 15-34 years, 35-54 years, 55-74 years,

and over 74 years) except for males aged 15-34 where cancer fell to fifth following accidents, suicide, homicide and HIV infection. Estimates of deaths in the United States for 1991 show even higher numbers with an expected figure of 514,000 people dying of cancer (272,000 male; 242,000 female). Most persons who have cancer survive months and even years while their eventual death often is caused by problems other than cancer. Also of note among these statistics is the fact that five year cancer survival rates have gone from 39% of all whites diagnosed with cancer and 27% of all blacks diagnosed with cancer in the period 1960 to 1963 to a five year survival rate of 52% for whites and 38% for blacks in the 1981 to 1986 period respectively. Estimates for the current period are for an additional two to five percent increase in both categories (Boring et al., 1991).

Conventional medical treatment of disease in humans assumes a curative perspective, removing illness and restoring the body to its normal functioning. The patient is viewed as passive as treatment is undertaken, and is expected to assume the sick and dependent role, which allows others to minister to him or her in their curative effort.

The majority of cancer research has concentrated on biological variables and on interventions that directly influence the chemistry or cellular structure of the body

(Zimpfer, 1992). It is increasingly apparent, however, that cancer must be viewed from a psychological and interpersonal perspective as well as a somatic one. Various cancers have stress correlates and can be treated from a psychosocial theoretical base as well as a physiological one (Harpham, 1992).

Psychosocial Aspects of Cancer

The connection between mental-emotional functioning and physical illness is not new to the field of medicine. The field of psychosomatic medicine was popular for a time about 1900-1920, then declined due to overgeneralized claims which could not be supported, such as the "migraine" or the "ulcer" personality (Zimpfer, 1992). Medical patients' experiences with psychosocial crisis has attracted considerable attention. Psychosocial disruption has been attributed to low self-esteem (Hunter, Linn, & Harris, 1982), acute anxiety (Wellisch, Jamison, & Pasnov, 1977), experience of loss (Blocher, 1976), self-directed rage (Sutherland, 1981), learned helplessness (Solomon, 1982), and decreased capacity for role performance and social involvement (Shanas & Maddox, 1976).

In the past 40 years many studies have linked the etiology and progress of cancer with psychological factors (Kowal, 1955; LeShan, 1956, 1959; LeShan & Worthington, 1956). LeShan (1966) analyzed life-history patterns of cancer patients and found the recurrent incidence of

overwhelming loss to be a precursor to the disease among these patients. He also found particular psychological factors that were present statistically more frequently in cancer patients than in noncancer control subjects. Simonton, Simonton, and Creighton (1978) proposed a cause and effect link between attitudes and thinking processes and the human body's limbic and immune systems and, hence, the production of cancer. In a literature review, Matje (1984) supported the general finding that some cancers have their basis in stress.

Despite considerable strides made in cancer treatment, including prolonging the lives of the victims of many types of cancer, cancer continues to be taxing both physically and psychologically. Oncology nurses have long recognized that the effects of cancer are much farther reaching than the biological aspects of the disease. A diagnosis of cancer affects the emotional, psychological and social structure of patients' lives as well as the lives of those around them (Pillon & Joannides, 1991). Not only is the diagnosis of cancer and its prognosis stressful, but the treatments themselves are threatening (Greer & Silberfarb, 1982; Hinton, 1973; Meyerowitz, Heinrich, & Schag, 1983).

Many Americans continue to equate cancer with death and a lack of a cure, leading to stress, anxiety, or psychological dysfunction.

Goldfarb, Dricsen, and Cole (1967) noted that early medicine recognized a relationship between dysphoric affect and cancer as well as a specific correlation between neoplasia (cancer) and psychological disorders. More recently the prevalence of psychiatric disorders among cancer patients has been the subject of much study (Derogatis et al., 1983; Levy, Heberman, Lippman, & d'Angelo, 1987; Massie & Holland, 1990). Massie and Holland (1990) reported that the most common types of psychological disturbance in cancer patients are depression and anxiety. While oth reactions are expected in response to the stresses of cancer, the patient often wonders if his or her emotional distress is "normal." The patient see these feelings as signs of weakness of character or wonder if they could somehow avoid giving in to their feelings if only they were stronger. Increasingly, patients are concerned that their normal depressed or anxious feelings will contribute to a negative outcome for their cancer treatment.

There are two specific psychological processes that can lead to increased distress in the treatment of cancer patients (e.g., chemotherapy) (Burish, Snyder, & Jenkins, 1991). First, Burish et al. (1991) have suggested an associative learning process in which particular aspects of the treatment setting or procedure become paired with aversive treatments. If this occurs, for example the

clinic itself or the sight of an IV, could elicit feelings of anxiety or depression. Research directed at these learned negative effects has suggested that a variety of psychological approaches, including relaxation training (Burish, Carey, Krozely, & Greco, 1987), systematic desensitization (Morrow & Morrell, 1982), and hypnosis (Redd, Andersen, & Minagawa, 1982), can be effective in treating these side effects.

The second factor contributing to the aversiveness of chemotherapy cancer treatment has received limited investigation. The majority of newly diagnosed cancer patients are not well informed about chemotherapy treatment nor are they prepared to cope with the psychological adjustments and stresses involved in such treatment (Burish et al., 1991). Most general medical patients receive some type of information regarding their illness and the specific treatment(s) they are to receive. This information routinely comes from the nurse, technician, or pharmacist just prior to the initiation of the treatment. This also is true for cancer patients. This information, however, typically addresses a specific set of problems and does not include coping information. Coping information that is provided is usually disseminated after the patient has begun the treatment process, thereby focusing more on problem resolution than on minimizing psychological distress.

Psychological Factors in the Outcome of Cancer Treatment

Data showing the adverse impact on medical treatment outcome when patients are experiencing psychiatric disorders are readily available (Blumberg, West, & Ellis, 1954; Bonadonna & Valagussa, 1981; Lesko & Holland, 1988). The incidence of depression in cancer patients is similar to that in comparably ill patients with other medical diagnoses (Bukberg, Penman, & Holland, 1984; Plumb & Holland, 1977). Severe anxiety or depression present in cancer patients has been found to have a link to a weakened immune system and impairments of physiological responses to cancer treatment (Levy, 1984). Perhaps more intriguing is the suggestion that patients with the most favorable outcomes are more frequently hostile than cancer patients who survive an average length of time (Stavraky, Buck, Lott, & Wanklin, 1968). An individual who has a favorable prognosis would appear then, to be a well-integrated person with considerable underlying hostility or aggressiveness, regardless of how he or she might appear on the surface. Longer survival and cure of patients with cancer have led to a new emphasis on understanding better methods of support for the psychosocial problems of cancer patients.

Psychosocial Intervention with Cancer Patients

Emotional reactions to cancer often include anxiety, depression, anger and hostility. A review of intervention

studies addressing the issue of psychological adjustment has shown that results have been positive (Edgar, Rosberger, & Nowlis, 1992). In a study in which counseling was provided to patients with diverse cancer diagnoses, psychological complications were reduced (Simonton & Simonton, 1975). Relatedly, Spiegel, Bloom, Kraemer, and Gottheil (1989), intending to "debunk" the whole psychological intervention hypothesis, conducted a carefully designed study using group therapy with patients who had metastasized breast cancer. They concluded after a ten-year follow-up that participants receiving psychosocial intervention through group counseling survived significantly longer than did controls.

There are at least a dozen clinical practices in the United States that specialize in psychosocial counseling for cancer recovery (Fink, 1988). The number of treatment sessions required has varied from 2 to 21, and the course of counseling sessions from six months to a year (Edgar et al., 1992).

Psychological Aspects Associated with Newly Diagnosed Cancer Patients

It is reasonable to assume that psychological forces are always at work, whether one is sick or not. "People are likely to be vulnerable and distressed in different ways, to different degrees and at different times in response to a host of different situations that endanger

them" (Weisman & Worden, 1976a, p.3). Receiving the diagnosis of cancer can be a significant stressor for most people. It carries with it implications regarding one's own mortality and the emotional reaction associated with the mere mention of the word cancer, and portends distressing, complicated, and unfamiliar side-effects associated with cancer treatment. In addition, there are the disruptions of work, social interactions and relationships, and family relations regarding extended family as well as spousal and/or parental responsibilities. Receiving a cancer diagnosis triggers anxiety and presents new challenges. Research has shown that patients react initially to a diagnosis of cancer in ways ranging from devastation to a reasonably good accommodation to the disease and its associated demands (Worden & Weisman, 1984).

In the lives of cancer patients, it is possible to distinguish the following phases of the disease, (Krause, 1991): the outbreak of cancer, the acute phase, and the rehabilitation phase of the disease. Each of these phases can be viewed in general terms as presenting the patient with demands for coping and adaptation. During the initial outbreak stage the major coping demand involves recognizing the disease and seeking help. It has been noted that newly diagnosed cancer patients face threats of disabling illness, mutilation, loss of an important body

part, loss of physiological functioning, or death (Mastrovito, 1972), and more recently the anxiety of survival with lives that are forever altered by the disease, the treatment, or both.

Informational Needs of Newly Diagnosed Cancer Patients

There is an increasing trend toward informing patients of their diagnosis, the diagnostic and therapeutic procedures they will undergo, and the prognosis of their disease (Cassileth, Zupkis, & Sutter-Smith, 1980). This is likely to continue because the heightened awareness of patients is regarded as an integral part of their complete health care (Antonovsky & Hartman, 1979; Cassileth, Zupkis, & Sutter-Smith). According to a larger scale study by Jones (1987) patients lacked information about their diagnosis, treatment, hospitalization, remission, and prognosis, as well as about implications for their physical, psychological and social well-being. They needed information pertaining to these factors soon after diagnosis. A lack of information regarding the immediate as well as the future implications of their disease, prohibited any anticipation of the results and thus impaired effective adjustment to them (Weisman & Worden, 1976b).

Derdiarian (1987) reported finding that needs for information soon after a diagnosis of cancer fall into four major categories of concerns: disease, personal,

family, and social. She noted that none of these are being adequately addressed on a routine basis for cancer patients.

Definition of Terms

This study will examine the relationship(s) between cancer and the psychological affects on individuals of a recent diagnosis of the disease.

Cancer: Cancer is a general term for the abnormal growth of cells. Sometimes something goes wrong in the process of cell division - a mutation that alters one or more of the cell's genes. A cell begins to multiply until it forms a concentrated area of these abnormal cells. By the time the abnormal area has reached a size that can be detected by medical procedures it will contain about one billion cells (Dollinger, Rosenbaum, & Cable, 1991).

Cancer may involve benign tumors or malignant tumors. Benign tumors can appear in any part of the body (e.g., freckles, moles, fatty lumps in the skin) and cause little problem from a medical standpoint. Malignant tumors, and on the other hand have two significant characteristics: a) they have no "wall" or clear-cut border. They put down roots and directly invade surrounding tissues, b) they have the ability to spread to other parts of the body. Bits of malignant cells fall off the tumor, then travel

like seeds to other tissues where they land and may start similar growths. This spreading cancer is called metastasis.

Almost all cancers share these two properties, although cancers arising in various organs tend to behave differently and spread to different parts of the body. They grow in very specific ways that are characteristic of that cancer. The consequence is that there is a specific method of diagnosis, staging and treatment for each kind of cancer. One set of principles governs diagnosis and treatment of breast cancer, for example, while the rules for lung or colon cancers are just as complex but somewhat different.

Cancer Treatments: The three mainstays of cancer therapy over the years have been surgery, radiation, and chemotherapy. These have now been joined by biological therapy which uses the body's immune system to combat growing cancer cells.

Surgery is the oldest and most successful approach to cancer treatment. If it is possible to cut it out safely and there is no residual disease, the patient may be cured. There are two surgical approaches. In the one-stage approach, the diagnostic biopsy might be followed immediately by the removal of the tumor which the patient is still under anesthesia. In the two-stage approach, only the biopsy is done. If the biopsy shows cancer, and

surgery is the treatment of choice, the operation to remove the tumor will then be carried out at some later date (Dollinger et al., 1991).

The purpose of radiation is to make tumors shrink or disappear. Radiation does this by damaging the genetic structure (DNA) of the tumor cells so they are unable to grow or divide. The damage is done by a beam of x-rays, gamma rays or electrons aimed directly at the tumor from a high energy x-ray machine or by radioactive materials placed inside or close to the tumor.

Chemotherapy is a term that is often misunderstood. It is a procedure which involves treating some medical conditions with chemicals (i.e., drugs). Treating an infection with penicillin or a headache with aspirin are in fact chemotherapy. When chemotherapy is mentioned in connection with cancer, the term generates a lot of fear. Many different drugs are used in chemotherapy treatment of cancer and have varying side effects. Some, but not all, of these side effects can be quite serious. While surgery and radiation treat cancers that are growing in one particular place, chemotherapy is generally used for cancers that have traveled through the blood and lymph systems to many parts of the body. In the past, chemotherapy was used only when surgery and radiation were no longer effective. Now it is the treatment of choice

for some kinds of cancer and is often used in combination with surgery and radiation, especially for localized cancers.

Biological therapy is a relatively new way to treat cancer. It takes advantage of the discovery that shows that the immune system may play a key role in protecting the body against cancer. The immune system might even play a part in combating cancer that has already developed. Biological therapy consists mainly of using highly purified proteins - interferon and interleukin-2 are the best known - to activate the immune system. In many different ways they boost the cancer-killing properties of lymphocytes which are specialized cells in the human immune system (Dollinger et al., 1991).

In recent years there has been great interest in using combination or multimodality treatment. Many aggressive forms of cancer therapy incorporate two or three of the standard treatment methods.

Newly Diagnosed Patients: Weisman and Worden (1976a) identify a period of approximately 100 days after a definite diagnosis of cancer as a particular phase of adjustment for cancer patients. Others report that the first year following diagnosis confirmation as a distinct stage of adjustment (Edgar, Rosberger, & Nowlis, 1991), although there is a continual transition occurring throughout the year. Patients who have just received

their diagnosis are quite different in psychological make-up from those who are one year post-diagnosis. Most research studies addressing the needs or situations of newly or recently diagnosed cancer patients treatments failed to note any particular time frame which would define the terms "newly diagnosed" or "recently diagnosed" (Derdiarian, 1987; Krause, 1991; Worden & Weisman, 1984). For purposes of this study, newly diagnosed patients are those who have received a definite diagnosis of cancer within 30 days of initiation of their participation in the study. Study participants will have received no treatment for their cancer prior to their first assessment for this study.

Psychosocial Oncology: Concern for the psychological well-being and quality of life among cancer patients is not new; however, the subspeciality of psychosocial oncology is a recent development in the field of oncology. It evolved from attempts to understand and address the psychological, emotional, and social effects of cancer on patients and their loved ones. Psychosocial oncology is a field in which research findings are very important but one in which treatment of the individual also is of paramount interest. The practice of psychosocial oncology covers the detection of psychological, psychiatric, and social morbidity, its diagnosis, and the design and implementation of treatment approaches for its alleviation

(Watson, 1991). Unlike other medical specialties, psychosocial oncology is not the property of any one group. It is a multidisciplinary field which utilizes the skills of nurses, oncologists, psychologists, psychiatrists, and counselors. Treatment methods in psychosocial oncology require a complete knowledge of the appropriate issues and skills in applying them. Moreover, the "tea and sympathy" approach in the care of cancer patients is being left to the less informed (Watson, 1991).

Anxiety: Anxiety states can be most meaningfully and unambiguously operationally defined by some combination of introspective verbal reports and physiological-behavioral signs (Spielberger & Sydeman, 1992). State anxiety (S-Anxiety) was defined by Spielberger, Gorsuch and Lushene (1970) as a temporal cross-section in the emotional stream-of-life of a person, consisting of subjective feelings of tension, apprehension, nervousness, and worry, and activation (arousal) of the autonomic nervous system. It is further assumed that S-Anxiety would vary in intensity and fluctuate over time as a function of perceived threat.

Trait anxiety (T-Anxiety) is defined in terms of relatively stable individual differences in anxiety-proneness (i.e., differences between people in tendency to perceive stressful situations as dangerous or threatening,

and in the disposition to respond to such situations with more frequent and intense elevations in S-Anxiety). It was further assumed that differences in T-Anxiety are reflected in the frequency that anxiety states have been experienced in the past, and in the probability that S-Anxiety reactions will be manifested in the future.

As an emotional state, state anxiety (S-Anxiety) consists of unpleasant, consciously-perceived feelings of tension, apprehension, nervousness and worry, with associated activation or arousal of the autonomic nervous system. Trait anxiety (T-Anxiety) has the characteristics of a class of constructs that Campbell (1963) has called acquired behavioral dispositions, and what Atkinson (1964) labeled as motives. Measures of T-Anxiety assess individual differences in the tendency to perceive a wide range of situations as dangerous or threatening, and to respond to these perceived threats with more frequent and intense elevations in S-Anxiety than persons low in T-Anxiety (Spielberger & Sydeman, 1992).

Distress: Distress, as it relates to cancer diagnosis and its treatment, is presented as a general mood disturbance by Cella, Jacobsen, Orav, Holland, Silberfarb, and Rafla (1987).They chose it as a dependent measure in research with cancer patients rather than some specific dimension (e.g., depression) because of accumulating evidence that psychological distress is

hierarchical, with the most information coming from one powerful underlying factor (Dohrenwand, Shrout, Egri, & Mendelsohn, 1980; Viet & Ware, 1983). In measuring general distress, Cella et al. (1987) assessed tension, depression, anger, fatigue, and confusion. They noted that it is important to assess mood distress in cancer patients as a separate entity whenever possible. The assumption that physically sicker or more impaired patients are necessarily more emotionally distressed is questionable. Cella et al. (1987) noted that measures of general distress should be validated against other objective measures of distress such as social adjustment, referral for mental health consultation, or non-compliance with treatment.

Sutherland, Lockwood, and Cunningham (1989) referred to the distress associated with cancer patients as a transient, fluctuating affective state assessed by six factors: tension/anxiety, depression/dejection, anger/hostility, fatigue/inertia, confusion/bewilderment, and lack of vigor/activity. Nine primary symptom dimensions are assessed by Derogatis, Morrow, Fettig, Penman, Piasetsky, Schale, Henrichs, and Carnicke (1983), in their measure of distress in cancer patients, the Symptom Checklist (SCL-90-R). These dimensions are somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic

anxiety, paranoid ideation, and psychoticism. In the current study general distress or total mood disturbance will be measured by the brief Profile of Mood States - Total Mood Disturbance Scale (POMS-TMDS).

Statement of Problem

This research will provide information regarding the efficacy of providing a structured educational program concerning treatment and coping strategies associated with a recent diagnosis of cancer as a means of reducing the anxiety and distress found during the early stages of the disease. This research will determine if information regarding treatment issues and coping with cancer can be effectively presented in a brief, one-time preparatory orientation module. Further, it will determine if presentation of such information presented to newly diagnosed cancer patients will result in a significant reduction in levels of anxiety and distress when compared to newly diagnosed cancer patients who receive only routine care from their health care team.

Research Questions

1. What will be the effect(s) on newly diagnosed cancer patients of a psychooncology intervention which includes preparatory and orientation components as compared to similar patients who receive only routine health care without psychosocial intervention?

2. Will the psychooncology intervention which

involve a preparatory/orientation program result in increased knowledge about cancer, cancer treatment and/or operation of the outpatient cancer treatment clinic, for newly diagnosed caner patients when compared to those newly diagnosed patients not receiving the intervention?

3. Will reductions in anxiety and distress maintain for at least seven to ten days following intervention?

4. Will the reports of distress levels made by individuals other than the patient indicate distress at levels similar to those indicated by the patient?

CHAPTER II

Literature Review

Before 1970, research on psychosocial issues related to cancer was noticeably absent (Cella, Jacobsen, & Lesko, 1990). There was no formal government support for related psychological research until the cancer control effort that began with the National Cancer Plan in 1972 (Holland, 1984). In 1981 a research conference identified six major areas for future research, the first of which was adaptation to cancer and psychosocial interventions to improve general adjustment. The other areas identified were biobehavioral interventions in behavioral medicine and their applications to cancer; behavioral and psychosocial research in childhood cancer; behavioral, psychological, and social determinants of cancer risk, prevention, and early detection; psychopharmacological applications to cancer; and attitudes, communication and teaching models (American Cancer Society, 1982). Since that time there have been a number of research studies that have addressed the issues of psychological, psychosocial and psychooncological aspects of cancer and its treatment.

The review of literature chapter will build a basis for this study from a framework of the following

categories: psychosocial aspects of cancer, psychosocial factors influencing cancer outcomes, and informational needs of cancer patients.

Psychological Aspects of Cancer

Patients' psychological reactions to cancer have attracted considerable empirical research. Many studies have focused on the prevalence of psychiatric disorders. It appears that many, but not the majority, of patients develop identifiable psychological symptoms (Goldberg & Cullen, 1985). Most of these cases are moderate rather than severe (Hughes, 1987). As a comparison base for these studies, psychiatric prevalence rates developed from general medical populations, tend to be consistently in the 12% to 30% range (Derogatis et al., 1983). Derogatis et al. found that 47% of a sample of oncology patients selected at random received a DSM-III diagnosis. Bukberg, Penman, and Holland (1984) found that 42% of a sample of 62 oncology inpatients had non-bipolar major depression using the DSM-III diagnostic criteria. Ninety-four of the 101 patients were found to have Axis I disorders. Beyond the presence or absence of psychiatric disorder, an important finding of the study involves the nature of the diagnoses made. More than two thirds of the diagnoses involved reactive conditions, with major mental illnesses comprising a relatively small proportion of the cases (Derogatis et al., 1983). Reactive types of adjustment

disorders are often responsive to psychological interventions and positive changes in medical status. When additional disorders or psychological conditions which also respond well to psychological intervention were included, the total proportion of patients with such conditions increased to 85%. This suggests that the pervasive psychological distress and dysphoria often associated with cancer may not be an inherent part of cancer, but rather a separate and potentially treatable condition (Derogatis et al.).

In examining one particular type of cancer, leukemia, Levinson and Lesko (1990) found that the most frequent emotional disorders encountered among adult victims of leukemia were anxiety, depression, and delirium. Anxiety in leukemia patients is either acute anxiety related to disease and/or treatment, or is either an exacerbation of a pre-existing anxiety disorder. Acute anxiety can develop at particularly stressful periods. Levinson and Lesko note five periods in the course of leukemia during which acute anxiety may develop; these are as follows: a) while awaiting the official diagnosis, b) before painful or frightening procedures, c) before major treatment, d) upon learning of relapse, and e) at personally meaningful events (e.g., anniversary reactions).

The diagnosis of a major depression in a medically healthy population relies heavily on the physical symptomology (e.g., weight loss or gain, sleep disturbance, appetite change, and lack of energy). In making the diagnosis of depression in a cancer patient, the presence of these neurovegetative signs is of little value as the disease itself or its treatments frequently produce these same effects. To determine the presence of depression in cancer patients one must rely on psychological symptoms: presence of persistent dysphoria or depressed mood, loss of self-esteem, undue pessimism, feelings of helplessness and hopelessness, a sense of worthlessness, and guilt, as well as frequent thoughts of death or suicide (Levinson & Lesko, 1990).

The third disorder frequently seen among leukemia patients is delirium which is a medical psychiatric syndrome of gross brain dysfunction involving difficulty with consciousness. This disorder is a direct effect of leukemia on the central nervous system. Treatment for delirium is purely of a biomedical nature.

There is a growing literature on the subject of psychosocial response to cancer. Studies of cancer patients who suffer serious visible disfigurement and impairment reveal that high levels of psychosocial disability are a result (Rozen, Ordway, Curtis, & Cantor, 1972; Sykes, Curtis, & Cantor, 1972). With regard to the

effects of mastectomy, Winick and Robbins (1977) found that more extensive surgery correlated with greater emotional distress and slower return to work. On the other hand a large questionnaire survey of breast cancer patients did not find any significant correlation between physical disability and psychosocial disability (Craig, Comstock, & Geiser, 1974).

Relatedly, other findings point to psychological and social variables. Poor morale or severe depressive symptoms early in the course of the illness appear to predict vocational and psychosocial difficulties up to two years later, as found by Schonfield (1972) in patients receiving radiation therapy. Massie and Holland (1990) note that responses to cancer may range from highly adaptive reactions similar to those found in individuals reacting to any catastrophic situation, to reactive anxiety and depression (i.e., adjustment disorder with depressed and anxious mood). Included in this range of reactions are indecision about treatment; differing levels of anxiety, distress or depression; sexual disorders; threats of violence to others; and even suicide (Massie & Holland). A Danish study examined cancer patients from 1971 to 1986 and found that the relative risk of suicide was significantly increased in the first two years after a cancer diagnosis, independent of age at diagnosis (Storm, Christensen, & Jensen, 1992). Surprisingly, the risk of

suicide has increased significantly among cancer patients in more recent years (Storm et al.).

In a study of 66 cancer patients, half recently treated for their disease and half long term survivors, three main response types were described: a) a significant number (29) were "doing well"; b) a minority (5) were coping satisfactorily with progressive disease; and c) an appreciable number (12) became psychologically and socially crippled by the cancer or its treatment (Mages et al., 1981).

Weisman and Worden (1977) offer a most convincing and comprehensive view of the relationship between a variety of factors and psychological outcomes. They found that the cancer patient with high emotional distress was likely to have the following characteristics: quite sick with advanced staging and many symptoms; received little support from others; viewed physicians as less helpful; used passive coping strategies such as suppression, fatalism, and withdrawal - strategies which usually did not adequately resolve problems; had low ego strength and high anxiety as measured on MMPI scales; came from a multi-problem background which may include problems with alcohol, marriage, and mental health; was of lower socio-economic status; and were infrequent church goers. Weisman and Worden estimated that perhaps half the

variance in emotional distress can be accounted for by medical variables, the remainder by non-medical issues.

Moos (1982) contended that crisis theory provides a conceptual framework for understanding psychosocial adaptation to severe illness such as cancer. It assumes that one's need for physiological homeostasis is paralleled by his or her need for social and psychological equilibrium. Experiences that upset one's normal pattern of behavior are met by habitual problem-solving mechanisms until balance is regained. However, some situations are so major that usual, habitual responses are inadequate. These experiences constitute a crisis and lead to a state of disorganization. Because people cannot remain in an extreme state of disequilibrium, some new balance must be reestablished. The new level of equilibrium may represent a healthy adaptation or a maladaptive response.

When cancer is diagnosed, anatomical staging is conducted to determine the type, location, and degree of metastases of the disease. Relatedly, Weisman (1979) has suggested that psychosocial staging can provide a framework for understanding the coping pattern of patients and families. He postulated four stages.

Stage One covers the first 100 days after diagnosis and is defined as <u>existential plight</u>. It begins with "impact distress" when patients first learn about their cancer. It is typically an alarming moment. Weisman

(1979) stated that one-third of his patients saw death as a real possibility regardless of the prognosis. This stage moves to "existential plight proper," with distress usually proportionate to the severity of physical symptoms.

Weisman (1979) labeled Stage Two as mitigation and accommodation. The length of this stage is indefinite, from those with an early cure to those whose condition worsens. The degree of adaptation varies widely. Successful copers reinvest in life and have open time perspectives. Less successful copers withdraw from life and develop closed time perspectives.

Stage Three encompasses decline and deterioration. It often begins with the reoccurrence and relapse of the disease. It represents a secondary existential plight.

Stage Four is defined as preterminality and terminality. It begins with signs of accelerating irreversibility, it is when dying begins. Patients often experience acceptance of death which provides a sense of distance from pressing problems. Associated worries about chronic problems become less important and distress is often reduced.

According to Hughes (1987) the psychological distress of cancer patients exists on a continuum from unhappiness and worry to depression and anxiety. The difficulty in distinguishing pathological mood states from natural

reactions to adverse conditions is pronounced when patients have cancer. Certain amounts of worry and unhappiness are expected and probably a prerequisite to realistic long-term adjustment.

Anxiety, with or without depression, is common for cancer patients (Brahnson, 1975; Hughes, 1987; Sutherland, 1981). It is often aroused by fears of unacceptability to other people, by a loss of activities through which patients have usually released anxiety, by an increase in family tension, and by an inability to perform well at usual roles (Bahnson, 1975). Vettese (1976) stated that cancer patients' anxiety involves fear of mutilation, fear of uncertainty of one's future, fear of progressive pain, and fear of death.

Depression often occurs as a reactive disorder in response to disruptions of one's basic adaptive patterns and to losses of significant roles and functions (Bahnson, 1975). It is frequently manifested through mental symptoms such a lowering of mood, dysphoria, loss of interest, sense of emptiness, an inability to feel any emotion, and withdrawal. Physical symptoms include loss of appetite and weight, fatigue and weakness, and loss of sexual energy (Brahnson, 1975; Hughes, 1987; Sutherland, 1981).

Psychosocial Factors Influencing Cancer Outcomes

With evidence of a significant psychosocial effect associated with cancer, the next logical question is how much effect is there on the course of the disease itself, and what effect is noted from psychosocial interventions. Increasingly patients are concerned that their normal anxious or distressed feelings will contribute to a negative outcome of cancer treatment. This seems to be related to the emphasis given emotions and cancer in the lay press, which has often reported stress, immunity, and cancer data uncritically. In fact, some patients ask for a "mental health check-up" before beginning treatment for cancer to be sure they are responding emotionally in a way that will assure the best response of their cancer to treatment (Massie & Holland, 1990).

Natural killer (NK) cells have been found to contribute to the remission from certain kinds of cancer, particularly breast cancer and those involving tumors. Natural killer cells are produced by the body and have been shown to slow or reverse the actual growth of cancer cells. Levy, Heberman, Lippman, and d'Angelo (1987). It is interesting to note, found that although neither radiation nor chemotherapy appeared to affect natural killer cell activity, thirty percent of natural killer cell activity level variance at three month follow-up were

associated with measures of fatigue and depression and lack of social support (Levy, et al., 1987).

Levy (1984) reports in summarizing her review of 30 research articles, that feelings of depression and helplessness appear to be associated with a shorter survival period, and feelings of anger and expressions of coping appear to be associated with longer periods of survival. In a preliminary study, Berkman and Syme (1979) found that longer survival for cancer patients is associated with psychiatric complaints, and that shorter survival is associated with a response that can be characterized as blandness in the face of stress. A study by Kronfol, Silva, Greden, Dembienski, and Carroll (1982) took a more direct look at the possible effects of depression or helplessness on the immune system. Using three groups of people including endogenously depressed patients, patient controls, and people who were not patients, a comparison of immune response was conducted. The researchers found a generalized and marked decrease in the lymphocyte responses of the depressed patients as compared to the responses of the other groups. Lymphocytes are an indication of a strong immune response. Again, poor psychological response appeared to be linked to a weakened immune response.

Social support has been positively associated with adjustment to cancer. Weisman and Worden (1975) reviewed

the survival patterns of 45 terminal cancer patients. They were assessed by interview and a battery of psychological tests. Multiple regression equations were used to predict survival times. Expected survival times for 35 of the patients who died were compared to actual length of survival. They found social support was positively related to length of survival. Holland (1977) studied patients with advanced cancer and found that emotional support and reassurance were more effective than medication in relieving depression and anxiety. It appears that patients who maintain close relationships with significant others demonstrate better adjustment to their illness than those who do not have supportive relationships.

Weisman (1979) also examined the coping patterns of patients experiencing high and low levels of psychological distress. Patients experiencing the most distress coped by suppression and passivity, fatalistic submission, isolation and withdrawal, blaming self and others, and excessive use of alcohol and drugs to reduce tension. Four coping patterns were used by patients with less distress: clarification and control (confront problems, give and receive information, redefine or reduce problems to manageable portions, consider alternative solutions); collaboration (sharing of concerns, trust problems to judgement of others); directed relief (ventilation of

feelings, temporary avoidance and suppression); and cooling off (moderate emotional extremes, distract, realistic resignation, build morale through increased self esteem).

Clearly, many of these findings are preliminary and correlational in nature. The accumulated evidence is all in the direction of an association between poor psychological response to disease and a lowered response to that disease and the reverse which is that a health psychological response is associated with a better disease course.

Informational Needs of Newly Diagnosed Cancer Patients

Several of the research studies discussed elsewhere in this chapter address the issues of psychological adjustment as it relates to a newly discovered diagnosis of cancer (e.g., Capone, Good, Westie, & Jacobsen, 1980; Gordon, Friedenbergs, Diller, Hibbard, Wolf, Levine, Lipkins, Ezrachi, & Lucido, 1980; Weisman, Worden, & Sobel, 1980;). According to Levinson and Lesko (1990) there are six universal problems that cancer patients encounter at diagnosis: a) issues surrounding death and the specter of life threatening illness; b) a forced dependency on family, spouse, and health care professionals; c) disfigurement and changes in body appearance and hence self-image; d) disabilities that can interfere with achievement of age appropriate roles and

tasks; e) disruption of significant interpersonal relationships from repeated hospitalizations and forced acceptance of the sick role; and f) discomfort and pain which can be part of any stage of cancer or its treatment. At diagnosis, a characteristic psychological reaction of initial shock and disbelief is followed by a period of emotional disequilibrium that includes episodic anxiety or panic attack, dysphoric or irritable mood, as well as the so-called neurovegetative signs (e.g., sleep disturbance and changes in appetite). Levinson and Lesko (1990) note that it is often helpful for the newly diagnosed patient to take an assertive stance, asking questions of the health care team, and developing the necessary trust in family, friends, and health care providers.

Krause (1991) conducted an exploratory study which used open-ended questions in a questionnaire and a semistructured interview to determine adaptation demands and a means which nurses could use in helping newly diagnosed patients to cope. She gathered information from 123 patients who had a variety of cancer types and were at various stages of the disease. Interviews were conducted with a subset of these patients. Contracting cancer had come as a "shock" to 68% of the patients, and they had reacted by employing various coping strategies including denial and rejection. Of the patients interviewed 72% reported having felt fear, sorrow, depression or

bitterness. Only 23% of the patients reported having taken the news of their illness calmly or having felt nothing at all. This 23% further reported that they had prepared themselves for the news they may have cancer, so diagnosis came as a sense of relief.

In this study, methods of coping reported by the patients were apparently directed toward the feelings and problems caused by the disease (Krause, 1991). Patients had tried to understand their disease and had collected information on cancer from medical books and other sources. Others sought support from their physicians, family, and friends. Additional avenues of coping with cancer included: a) emotional evaluation of the situation ("Crying is of no help, one must put up a fight"); b) evaluation on the basis of an earlier comparable predicament ("I have gotten by before"); c) comparison with patients who had recovered from cancer; d) hope; e) social activity or work; f) religious help; g) comparison with patients who had dies of cancer (looking for dissimilarity); and h) passive measures such as denial or attempts to forget the disease.

Weisman and Worden (1976b) identified a poorly recognized but significant period in the course of cancer which they called the existential plight. This period begins with the definitive diagnosis and continues for two to three months into the illness, approximately 100 days.

The major signs during this period are the predominance of life or death concerns, even over worries about health or physical symptoms. Weisman and Worden (1976b) investigated this phenomenon in a study in which 120 newly diagnosed cancer patients were interviewed, tested and followed at four to six week intervals for four months, beginning ten days after diagnosis. Plight was analyzed from the viewpoint of coping strategies, resolution of problems, vulnerability, total mood disturbance, and predominant concerns. Patients who had higher emotional distress during this period had many regrets about the past, were pessimistic, came from a multiproblem family, and had marital problems. The widowed or divorced had higher vulnerability, as did patients who anticipated little or no support from significant others. Although vulnerability increased with more symptoms or further advanced cancer, at the time of diagnosis psychological distress crossed diagnostic and prognostic boundaries, enabling investigation to predict within limits those patients who would cope effectively or fail to cope well with cancer and its ramifications.

In a follow-up study, Worden and Weisman (1984) noted that the highly distressed patients did not have significantly more problems than low distressed patients, but showed an inability to generate a number of alternatives coping strategies and seemed to overuse

ineffective strategies. They designed and researched two interventions with the noted deficiencies in mind. The first intervention was based on a psychotherapeutic model which was patient-centered, focused on specific problems the patient was facing at the time, and ways such problems could be handled. The therapist's role was described as facilitating problem identification, encouraging expression of appropriate affect and engaging the patient in exploring various ways of problem solving. Behavioral rehearsal and role playing were also included in some cases.

In this study, the second intervention focused on common problems that cancer patients in general encounter in the course of coping. It was more didactic, drawing from cognitive skills training and behavior therapy. Both interventions were limited to four sessions. Therapists were encouraged to adhere to a specific protocol and discouraged from using unstructured interviews. Fifty-nine patients received one of the two interventions. A control group of 58 received no intervention. All were followed at two-month to six month intervals by interview and testing using the Profile of Mood States, Index of Vulnerability, and Inventory of Current Concerns. There was a significant lowering of emotional distress in the intervention groups as compared to the control group. There was also a significant increase in the level of

problem resolution in the intervention groups, although the number of problems experienced by both groups were not different. Patients were randomly assigned to one of the two treatment groups. Both interventions were equally effective in reducing distress. The number and types of problems reported by patients during the follow-up period were not different in the two groups and levels of problem resolution was comparable for both groups.

According to Christ (1991) in presenting a model for psychosocial intervention, there are four tasks that need to be confronted by the cancer patient during the diagnosis stage of cancer: a) coping with the confrontation with one's own mortality; b) coping with the emotional overwhelm that is a part of the diagnosis process; c) moving from denial of the reality of the disease to constructive processing of disease and treatment information; and d) making decisions about the appropriate treatment. All patients reported that the diagnostic process involves a confrontation with the reality of one's mortality, even if the biopsy proved to be negative. They are emotionally overwhelmed and often say that for them life will never be the same again because they will always have a heightened sense of their own personal vulnerability. Interventions need to be aimed at ways of quickly reducing patient's anxiety in

order to enable them to integrate the information they need to make vital treatment decisions (Christ, 1991).

Critical interventions during diagnosis include education, the provision of information and crisis intervention. In fact, there are few programmatic interventions offered systematically to patients and their families during the diagnostic process and shortly thereafter (Christ, 1991).

Studies show that cancer patients generally seek maximum information about their disease as a way of gaining control of their predicament (Kruhtz, & Shultz, 1979; Mages & Mendolshon, 1979; Rotter, 1987; Weisman & Worden, 1976a). McIntosh (1977) documented the selectivity of these patients regarding their diagnosis, treatment and prognosis. In later studies, the behavior of cancer patients indicating their need to gain control through seeking information are reported by Cassileth, Zupkis, and Sutter-Smith (1980), and Rotter (1987).

Psychological Intervention With Cancer Patients

As the research indicates that there is an association between depression, anxiety, distress or helplessness and lower survival rates and that there is also an association between a sense of coping and higher rates of survival then the question must be asked: can depression, anxiety, distress or helplessness and the lack

of coping among cancer patients be altered? And, if they can, will the change affect the outcome of the disease?

The answer to the first question is undoubtedly yes. The strategies for change are numerous. Petersen (1982) has suggested that medical practitioners adapt for use with patients the type of strategies that dispel helplessness in animals, that a physician enlist patients as collaborators in their own treatment, explaining to them that their progress depends on this assistance.

Cain, Kohorn, Quinlan, Latimer, and Schwartz (1986) compared individual and group therapy formats for a structured intervention for women with gynecologic cancer. The intervention had eight components including discussion of the causes of cancer at diagnosis, impact of the treatment(s) on body image and sexuality, relaxation training, emphasis on good dietary and exercise patterns, communication difficulties with medical staff and friends/family, and setting goals for the future to cope with uncertainty and fears of recurrence. Seventy-two women participated in an individual intervention, a group intervention, and no-treatment. Outcome measures were standardized and included depression and anxiety interviewer rating scales and a psychosocial adjustment to illness scale which were administered pre- and posttreatment and at a six-month follow-up. Posttreatment analyses indicated all groups improved with time; however,

interviewer rated anxiety was significantly lower for the individual therapy subjects only. In six-month follow-up no differences between the intervention formats, but both groups reported less depression and anxiety and better psychosocial adjustment (including health perspectives, sexual functioning, and use of leisure time) than the no-treatment control group.

Ferlic, Goldman, and Kennedy (1979) conducted a research study with patients in the advanced stage of cancer. The study involved an interdisciplinary crisis intervention program that included patient education, presentations by medical team members, and supportive group therapy. Sixty adults (30 intervention and 30 no-treatment controls), with advanced cancer participated. Outcome measures were experimenter-deprived and assessed hospital adjustment, communication with others, disease information, death perceptions, and self-concept. Analyses indicated the intervention group improved across all areas. The self-concept score for the intervention group significantly increased, whereas for the control group significantly decreased.

Teaching Coping Skills. The coping skills approach involves structured training in specific behavioral, cognitive and affective competencies for managing the disruptive effects of cancer (Telch & Telch, 1985). The coping skills approach assumes that the distress

experienced is partially due to a limited or ineffective skills repertoire. Within a social framework, treatment is viewed as an educational enterprise with the emphasis on assisting patients to develop a repertoire of coping skills that will enable them to manage stressful situations effectively. Skills which are not commonly among individual's coping alternatives such as relaxation techniques, problem-solving, and self-instructional training are taught. Often these skills are taught in the context of supportive group therapy as noted above in the study by Spiegel and Bloom (1983) for example.

Burish and Lyles (1981) carried out a study in which they provided strong support for the effectiveness of progressive muscle relaxation and guided imagery for reducing distress associated with chemotherapy treatment, particularly nausea and vomiting. Patients in this study were randomized to either relaxation training or a no-treatment control. In a subsequent study Lyles, Burish, Krogley, and Oldham (1982) randomly assigned 50 cancer patients to either: a) progressive muscle-relaxation plus guided imagery; b) therapist control, in which a therapist provided encouragement and support with no relaxation training; or c) no-treatment control. Anxiety, depression, nausea and vomiting were assessed on self-report, physiological, nurse rating and home record indices. The result of both studies indicated that

patients who received relaxation training were significantly less anxious and depressed, demonstrated less physiological arousal and reported less severe nausea and vomiting during chemotherapy. Morrow and Morrell (1982) examined the perception of control as a way to mediate reductions in patient distress and adverse response to chemotherapy. They conducted a randomized trial in which they compared the effectiveness of a systematic desensitization procedure, client-centered supportive counseling and a no-treatment control for reducing frequency, severity, and duration of anticipatory nausea and vomiting in 60 cancer patients. Nausea was measured by patient self-report as were anxiety (State-Trait Anxiety Inventory) and feelings of control. A significant decrease in the frequency, severity and duration of anticipatory nausea and vomiting was reported by patients receiving systematic desensitization as compared to patients receiving supportive counseling or no-treatment.

Self-instruction and problem solving procedures have also been studied with cancer patients. The aim of these techniques is to fortify coping skills by learning a problem-solving process for generating alternative coping strategies and evaluating their effectiveness. Weisman, Worden, and Sobel (1980) randomized newly diagnosed cancer patients evaluated as being at "high risk" for emotional

distress to either: a) generalized problem-solving and self-instruction condition that included relaxation training (N = 30), or b) a personalized problem-solving and self-instructional condition (N = 29). In both treatment conditions problem-solving was emphasized. The major distinction involved a differential focus on either solving a patient's personal problems or teaching a specific step-by-step problem-solving process that could be applied to problems in general. Data collected during an earlier 1976 study to validate a screening instrument (N = 58) were used as control measures. The authors stated that they used this earlier data as a control condition because they felt it unethical to withhold intervention from "high risk" patients in their 1980 study. Patients in both treatment conditions, as compared to control subjects, demonstrated significant improvement on the Profile of Mood States and on several author constructed measures of emotional distress. Intervention patients had higher problem resolution scores than controls although both were similar in the number of reported problems. Treatment gains were maintained at 2, 4, and 6 month follow-up assessments. No differences were found between the two active treatment groups and both were superior to the untreated controls at 2, 4, and 6 month follow-ups.

Christensen (1983) reported on an intervention for adjustment difficulties of mastectomy patients and their partners. The program was very structured and included discussion of the relationship, readings, and discussions of the emotional and sexual aspects of mastectomy, disclosure of feelings and fantasies of the self and the spouse, and other exercises (e.g., communication training and role playing) to facilitate confronting and solving problems. Twenty women, ten intervention and ten no-treatment control participated. For outcome measures, the author utilized the Beck Depression Inventory (BDI), the State-Trait Anxiety Inventory (STAI), self-esteem, marital adjustment, sexual satisfaction, and locus of control assessments pre- and posttreatment. Analyses indicated the intervention had modest effects in reducing distress for the breast cancer patients, but significant improvements in self-report sexual satisfaction were found from both the woman and her partner.

Individual Counseling. A number of studies have evaluated programs in which patient were seen individually. The advantage of this approach is that the therapist or counselor can tailor the number and length of sessions to an individual patient's needs and thereby offer a more flexible service. In one study Capone, Good, Westie, and Jacobson (1980) examined the response of newly diagnosed gynecological cancer patients to individual

therapy with female psychologists. They found no difference between the intervention group and a no-treatment control group matched on a diagnostic criteria basis on a measure of mood disturbance. Counseled patients had a clearer self-image and more of them returned to work and prior sexual functioning at a 12-month follow-up.

Similarly, individual supportive counseling delivered by a team of oncology counselors was delivered to a group of newly diagnosed patients with breast cancer, lung cancer, or melanoma (N = 157). When compared to a no-treatment control group with the same types of cancer (N = 151) the intervention group's negative affect declined more rapidly after discharge (Gordon et al., 1980).

Linn, Linn, and Harris (1982) found no differences between patients receiving individual counseling and a control group when depression was assessed one month after intervention. After three months of individual therapy sessions depression was found to be significantly decreased. The patients studied were all male and in the later stages of advanced cancer (N = 34) with a matched control group (N = 24). In addition to a decrease in depression, measures of quality of life, internal control, and self-esteem increased. Survival rates were unaffected by the intervention.

In a study which utilized specialist nurse counselors to deliver individual counseling to mastectomy patients Maguire, Tait, Brooke, Thomas, and Sellwood (1980), found that after four months a post-operatively counseled group showed more anxiety than a matched, no-treatment control group. At 12-18 months, however, the trend reversed with controls showing more anxiety. The reduction in anxiety was explained by a high rate of psychiatric referral and intervention in the counseling group.

Educational/Informational Approaches. The most rudimentary methods of psychosocial cancer intervention typically include relaxation and mental imaging, encouragement for more accurate beliefs about the progress and treatment of cancer, and inclusion of a healthier life-style (e.g., exercise and good nutrition). The wellness model for cancer treatment (Zimpfer, 1992) includes all of these elements in a holistic approach to cancer. Other approaches have utilized stress inoculation training to reduce anxiety in adolescents (Tucker, 1983); a computerized telephone outreach system to assess and address the needs of outpatients with advanced cancer who are receiving chemotherapy (Siegel, Mesagno, Karus, & Christ, 1992); and specific psychotherapy for cancer patients who are seeking unorthodox or questionable medical treatment (Cassileth, 1991).

In the successful coping patterns the majority of what has been effective concerns obtaining and using information. Cohen and Lazarus (1979) contend that while information seeking is but one mode of coping with a stressful situation it is important because it may act to mediate between the individual, the stressful event, and the coping behavior. Previous research has shown that patients develop more accurate expectations about threats of physical harm when they receive information regarding it (Janis & Leventhal, 1965). Having gained information regarding threats, patients consequently coped more effectively with such threats through problem solving and reduction of emotions (Johnson & Leventhal, 1974).

Although cancer shares many characteristics with other potentially fatal diseases, the diagnosis of cancer introduces stresses of its own because patients presume that it is invariably lethal, painful, debilitating, and distancing from others (Stewart, 1980). Houts, Rusenas, Simmonds, and Hufford, (1991) conducted a review of literature related to information needs of families of cancer patients. They identified a number of potential causes for the unmet information needs including limited contact with physicians and no initiative taken for communication.by health care staff unless the patient's condition worsened. Houts et al. (1991) suggested strategies for meeting these informational needs included:

a) generic information that can be made available through booklets, video tapes or other mass produced materials, and b) patient-specific information provided by the patient's health care professional. Northouse and Northouse (1987) concluded that one of the major issues confronting families members of cancer patients as well as many of the patients themselves is the acquisition of information. Tringali (1986) also found that the highest priority for families of cancer patients, regardless of the stage of the disease, was information about the disease, its treatment and prognosis.

Obtaining information was more important for the patient during the early stages. The cancer patient him or herself may appear to desire to be kept in the dark regarding the particular details of their disease but usually respond better once they have the information (Northouse & Northouse, 1987). Derdiarian (1987) also found that cancer patients not only seek information regarding their condition significantly more often than not, but those who seek that information and are successful in gaining that information show reductions in anticipation of harmful outcomes and make fewer demands on medical staff for pain or discomfort reducing measures (i.e., medication to reduce nausea).

As noted above, the effects of a combined patient education and supportive counseling intervention was reported by Gordon et al. (1980). This study provided some support for the effectiveness of a combined supportive and educational approach for reducing psychological distress. Additionally, the study by Ferlic et al. (1979) involved an interdisciplinary program with patients in the advanced stages of cancer. This study, as well, provided support for the use of patient education in combination with group therapy.

Jacobs, Ross, Walker, and Stockdale (1983) reported on two concurrent studies aimed at assessing the effects of patient education or support group therapy with 81 Hodgkin's patients. In each of the respective studies the active treatment (either patient education or support group therapy) was compared to a no-treatment control. Patients assigned to the education treatment were mailed a 27-page booklet about Hodgkin's disease, while patients in the support group condition received eight weekly, 90-minute sessions. Support groups were attended by an oncologist, psychologist, and social worker and focused on issues of concern to members (e.g., treatment side effects, impact of cancer on work, family, and interpersonal relationships). Patients' knowledge regarding their disease was tested pre- and post-intervention. Patients also completed the Cancer Patient

Behavioral Scale (CPBS). Patients receiving the education booklet improved significantly on the CPBS subscale measures of anxiety, treatment problems, depression, life disruption and disease knowledge as compared to the controls. Patients in both the support group treatment and support group control showed some improvement over the study period but were not significantly different at the eight-week program termination on any of the measures.

Jacobs et al. (1983) explained the positive results from the educational counseling as being a function of the patients' increased knowledge concerning their illness. However, the effects of increased knowledge on psychological adjustment may be mediated in part by changes in self-perceptions regarding one's prognosis brought about by newly acquired information.

Johnson (1982) found a significant decrease in anxiety and an increased sense of meaning in life among patients who had participated in a four-week patient education course. Similarly, Dodd (1988) reported a positive improvement in anxiety in a group of chemotherapy patients six weeks after they had been given information on self-care.

Cassileth, Heiberger, March, and Sutton-Smith (1982) presented four audiovisual programs to a total of 240 cancer patients, their families and friends. The programs each approximately 14 minutes in length, covered the

following topics: a) chemotherapy, b) radiation therapy, c) common questions about cancer, and d) pain and sleep disturbances. Questionnaires were completed before and after viewing the videos. Outcome measures included the State-Trait Anxiety Inventory (STAI) and an author produced knowledge test. The results indicate that audiovisual presented information can substantially increase patients' understanding of their disease, decrease anxiety, and facilitate communication among patients, families and physicians. Cassileth et al. also reported that the programs appeared to be especially useful with less well educated and nonwhite patients.

From their review of patient education literature, Fernsler and Cannon (1991) compiled the following "empirically validated" benefits of cancer patient education: a) increased knowledge, b) enhanced self-care (chemotherapy side-effect management, pain management, ostomy care), c) reduced disruption in daily functioning, d) reduced anxiety, e) enhanced self-concept and self-esteem, f) increased satisfaction with care, g) improved pain control, and h) improved health of mouth and throat.

In answer to the question of whether one therapeutic approach has advantages over another, the evidence suggests there are no real differences. This latter area needs some clarification. If intervention studies were to adopt similar techniques of evaluation, this would improve

comparability between programs and allow some definite conclusions to be drawn. Also, it is not always clear what people expect to achieve by offering support and there is sometimes confusion about the aims of a specialist support program. This can be remedied by stating specifically, rather than in general terms, what the aims of an information program are to be. The assumption that any support is beneficial, no matter what form it takes, is dangerous. Some programs may provide limited benefit to patients and there is a risk that, for a few people, intervention may cause unnecessary distress in the process of trying to change their psychological responses. One point is clear: more research is needed on the effectiveness of psychosocial intervention before it can be assumed that support should be provided as a matter of course.

CHAPTER III

Methodology

Hypotheses

The hypotheses for this research study are stated in the direction of the expected findings, given findings from previous research reported in Chapter II.

1. Newly diagnosed cancer patients who receive outpatient treatments and are presented with the preparatory/orientation module (see independent variable, p. 85) will show significantly reduced levels of state anxiety (S-Anxiety) and distress when compared to newly diagnosed patients who are scheduled to receive outpatient treatments who receive only the prescribed care from their health care team.

2. Newly diagnosed cancer patients who receive the preparatory/orientation module will demonstrate a higher level of knowledge of cancer clinic functioning and availability of resources than newly diagnosed cancer patients who do not receive the preparatory/orientation module.

3. Seven to fourteen day follow-up measures of newly diagnosed cancer patients who received the preparatory/orientation module will show levels of anxiety and distress that continue to be significantly reduced

when compared to newly diagnosed cancer patients who received only usual care from their health care team.

Study Participants

This study examined the levels of anxiety and distress in adult patients who had new diagnoses of cancer and were scheduled to receive outpatient treatment. The participants were referred by their physician and scheduled for treatment through the outpatient Hematology/Oncology clinic at the North Carolina Baptist Hospital and Comprehensive Cancer Center of Wake Forest University in Winston-Salem, N.C. There were 136 patients scheduled to participate in the study (70 assigned to the treatment condition and 66 assigned to the control condition). Of the 136 assigned, 117 completed phase I of the study and 92 completed all phases of the study (44 received the treatment and 48 were in the control group).

The study participants had an average age of 55.6 years (range = 21-85). The average ages of participants in the intervention group and control group was 55.8 and 55.4, respectively. There were 20 males and 24 females in the intervention group; the control group contained 25 males and 23 females. All patients were caucasian except for four African-Americans in each of the two groups. The specific types of cancer represented in the intervention group included breast cancer (12), lung cancer (7), leukemia/lymphoma (7), pancreas (2), colon/rectum (2), one

case each of melanoma (skin cancer), stomach, prostate, utero and urinary. There were nine cases in which the cancer site was unknown or not stated. The types of cancer represented in the control group included breast cancer (11), lung cancer (8), leukemia/lymphoma (8), colon/rectum (5), one case of prostate cancer and 15 cases in which the cancer site was unknown or unstated.

Counselor

One counselor was primarily responsible for conducting all sessions with the patients. The counselor was a female with a Bachelors degree in education, a teaching certificate and five years experience teaching elementary school. She has recently completed a Masters degree in Education in the field of counseling with specialization in community counseling. As a part of her graduate training she completed 600 hours of internship at the Comprehensive Cancer Center where the study was conducted. The counselor met with the director of the Cancer Patient Support Program and the author prior to the initiation of the study to review the treatment and control procedures and all data collection methods. The counselor then provided the primary investigator a mock session of the preparatory/orientation module, followed by feedback and discussion of the procedure. This was completed to assure that sessions were conducted as

planned. The counselor and primary investigator met on a weekly basis to discuss progress and address any problems.

Dependent Measures

Participants were assessed for levels of anxiety using the State-Trait Anxiety Inventory (STAI Form Y) (see Appendix A) (Spielberger, Gorsuch, & Lushene, 1970). Levels of distress were assessed by the short form of the Profile of Mood States (see Appendix B) (McNair, Lorr, & Droppleman, 1971) known as the Brief Profile of Mood States, Total Mood Disturbance Score (Brief POMS-TMDS) (Cella, Jacobsen, Orav, Holland, Silberfarb & Rafla, 1987; Shacham, 1983). The author developed Oncology Clinic Questionnaire (see Appendix C) was developed to assess the patient's knowledge of the information being provided by the treatment intervention. In order to assess levels of patient distress as perceived by his or her identified support person a modified version of the Brief POMS-TMDS was developed (see Appendix D).

State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory was developed by Spielberger, Gorsuch, and Lushene (1970) to provide reliable, relatively brief, self-report scales for assessing both state and trait anxiety. The State-Trait Anxiety Inventory has been used extensively both for research as well as for clinical purposes. It is a self-report measure consisting of 20 questions which measure

state anxiety (S-Anxiety), defined as how an individual feels "right now, at this moment;" and an additional 20 questions which assess trait anxiety (T-Anxiety) which is how one feels generally. The STAI (Form Y) is presented at approximately a sixth grade reading level. It generally requires 20 minutes to complete both scales.

The STAI (Form Y) was normed with working adults, college students, high school students, and military recruits. It has not been specifically normed with cancer patients. The test-retest stability coefficients for the T-Anxiety scale are reasonably high, ranging from .73 to .86 for college students to a range of .65 to .75 for high school students. In contrast, stability coefficients for the S-Anxiety are relatively low, with a median of only .33 (Spielberger, 1983). This lack of stability is to be expected, however, because a valid measure of state anxiety should reflect the influence of unique situational factors that exist at the time of testing.

Spielberger (1983) has suggested that since anxiety states are expected to vary in intensity as a function of perceived stress, measures of internal consistency such as alpha coefficients provide a more meaningful index of the reliability of state measures than test-retest correlations. A median coefficient of .93 was obtained for the S-Anxiety scales (situational) with only one sample below .90. The T-Anxiety scales had equally good

internal consistency with a median Alpha of .90. Since the distribution of scores on the STAI S-Anxiety scale when given under neutral conditions is positively skewed, alpha reliability coefficients are generally slightly higher when this scale is given under conditions of psychological stress (Spielberger & Sydeman, 1992).

Items for the STAI were originally selected on the basis of significant correlations with the Manifest Anxiety Scale (MAS) and the IPAT Anxiety Scale (ASQ), the two most widely used anxiety measures at the time of the development of the STAI (Spielberger et al., 1970). It was noted that the MAS contains a number of items that reflect depression rather than anxiety (Spielberger & Sydeman, 1992). In the revised STAI (Form Y), items with depressive content were eliminated (Spielberger, 1983). The relatively high correlations of scores on the STAI T-Anxiety scale with the ASQ and the MAS, ranging from .73 to .85, have indicated a high degree of concurrent validity (Spielberger, 1983). A major advantage of the STAI T-Anxiety scale is that it provides a measure of anxiety that is much less contaminated with depression and anger (Spielberger & Sydeman, 1992).

Evidence of the construct validity of the T-Anxiety scale is reflected in the mean scores of various neuropsychiatric patient groups as compared with normal subjects. The STAI (Form Y) significantly discriminates

between normal individuals and psychiatric patients for whom anxiety is a major symptom. In addition, general medical and surgical patients with psychiatric complications have higher T-Anxiety scores than general medical and surgical patients without such complications (Spielberger, 1983).

Spielberger (1983) has suggested that evidence of the construct validity of the STAI S-Anxiety scale can be noted in the finding that the S-Anxiety scores of college students are significantly higher under examination conditions and lower after relaxation training than when they were tested in a regular class period. Spielberger and Gorsuch (1970) originally reported a high correlation (.70) between the STAI and the Cornell Medical Index, indicating a correlation between medical symptoms and anxiety as measured by the STAI.

Since first introduced a quarter century ago, the STAI has been used in more than 6000 studies (Spielberger & Sydeman, 1992). It has been used extensively in psychological research in many areas, including experimental investigations and clinical studies of stress-related psychiatric, psychosomatic, and medical disorders and as an outcome measure in research on the effectiveness of psychotherapy, biofeedback, and various forms of behavioral and cognitive treatment (Spielberger & Sydeman, 1992).

Brief POMS-TMDS

The 65-item Profile of Mood States (POMS) was designed to measure the level of total distress being experienced (McNair et al., 1971). The POMS provides a summary measure of distress, the Total Mood Disturbance Score (TMDS). It has been reported in the literature that there is one powerful underlying factor contributing to psychological distress (Dohrenwend, Shrout, Egri, & Mendelsohn, 1980; Viet & Ware, 1983). While the POMS contains six factorially derived subscales (Tension, Depression, Anger, Fatigue, Confusion, and Vigor), the discriminative validities of these separate subscales are questionable (Cella et al., 1987). Along these lines, the POMS manual itself reports very high Anxiety ("Tension") to Depression intercorrelations, ranging from .56 to .77 (McNair et al., 1971).

While the 65-item POMS takes approximately 5-7 minutes for healthy individuals to complete, it can require up to 20 minutes for physically ill patients to complete (Shacham, 1983). The POMS has proven to be effective measure of general distress (Tanaka-Matsumi & Kameoka, 1986); however, it is somewhat long for use with multiple questionnaires and with physically ill patients. A shorter 17-item Brief POMS TMDS has been developed (Shacham, 1983) and has been found very useful in measuring mood disturbance associated with treatment in

cancer patients (Cella et al., 1987; Holland, Korzun, Tross, Silberfarb, Perry, Comis & Oster, 1986; O'Malley, Foster, Koocher, & Slavin, 1980; Taylor, Lichtman, Wood, Bluming, Dosik, & Leibowitz, 1985; Wells, 1992), degree of physical impairment (Cella, Orofiamma, Holland, Silberfarb, Tross, Feldstein, Maurer, Comis, Perry, & Green, 1986), extent of cancer disease (Cella et al., 1986) and pain related to cancer (Shacham, Reinhardt, Raubertas, & Cleeland, 1983). The Brief POMS-TMDS was developed by specifying that only one factor, which would presumably reflect general distress, be derived from the 65-item TMDS. The resulting Brief POMS-TMDS has 17 items (Cella et al., 1987).

Internal consistency of the 17-item scale was found to have a Cronbach's alpha of .91, whereas it was .93 for the 65-item TMDS. The Brief POMS-TMDS correlated significantly with the POMS ($r = .93$) (Cella et al., 1987). Validation was based on a comparison between Brief POMS-TMDS scores for pancreatic cancer patients and gastric cancer patients to POMS-TMDS scores for the same type of patients. Similar scores as well as the fact that pancreatic cancer patients scored higher than gastric patients on both measures was offered as initial evidence of validity.

Given that items from five of the six original POMS subscales emerged as part of the Brief POMS-TMDS, it is

unlikely that the Brief POMS-TMDS is measuring only a single component of distress. The one subscale which is not represented (Vigor) tends to measure physical rather than emotional or psychological well-being (Cella et al., 1987). Its omission from the Brief POMS-TMDS has suggested that this shortened scale may be closer to a pure measure of psychological distress than the POMS. The high correlations between the Brief POMS-TMDS and the POMS provide supporting justification for using the brief form when the measurement of distress alone is the goal.

The Brief POMS-TMDS is an adjective rating scale made up of 17 items. Each items involves a five-point Likert-type rating of feelings rated from 0 for NOT AT ALL to 4 for EXTREMELY. The items are presented on a seventh grade reading level (McNair et al., 1971).

Modified Brief POMS-TMDS

The modifications to the Brief POMS-TMDS consisted solely of changes in the instruction to direct the person completing the scale to do so with the patient in mind rather than him or herself (see Appendix D). Each of the modified Brief POMS-TMDS scales will be designated for the individual designated as a support person by the patient on the Background Questionnaire (see Appendix E).

Oncology Clinic Questionnaire

The Oncology Clinic Questionnaire (OCQ) was developed through consultation with experts in Psychology Services

and the Cancer Patient Support Program at Bowman-Gray School of Medicine and the Counseling Department at the University of North Carolina at Greensboro. Individual items of the OCQ, as with the specifics of the treatment intervention were suggested by patient questions and concerns expressed over the years. The questionnaire contains 26 items which seek yes or no responses regarding clinic operations, with a five point Likert scale assessing the helpfulness of the information if "Yes" is indicated, five items concerning the patients confidence in his or her medical care and the stress experienced in the past week, and three questions regarding the type of treatment the patient is receiving and comments regarding the clinic visit (see Appendix C).

Background Information

Data also was collected on such demographic information as age, gender, cancer site, and educational level (see Appendix E). Post hoc examination of this data will be made to determine if there are specific trends noted based on any of these factors or their interactions.

Session Analysis

In order to provide an analysis of the counseling session, which makes up the third component of the treatment intervention (the question and answer component), the sessions were audio taped. An analysis was then made of the content of the sessions related to

the types of questions or concerns the patients brought to the session (see appendix N). The question and answer sessions lasted approximately 5 to 15 minutes. The tapes of the patient's responses were listened to by the primary investigator and categorized into one of the following categories:

1. Medical/Physical. This included questions regarding the potential treatment to be received, likely treatment outcomes, side effects, or possible course of the disease. These questions were listened to by the counselor but referred to the health care team for answers.

2. Administrative/Procedural. This included questions about the functioning of the hospital or clinic, the location of specific areas in or about the hospital or in the City of Winston-Salem (many patients were from out of town), or the names or roles of individuals in the clinic or hospital. The counselor provided the information.

3. Personal/Interpersonal. This included the expression of fears, concerns, or emotional responses associated with the disease, the clinic visit, or perceived by the patient to be disease-related. The counselor listened and offered emotional support. It

was often appropriate to remind the patient of the resources available that are listed on the information sheet provided (see Appendix J).

Treatment Procedure

Participants in the study were drawn from patients already scheduled in the outpatient clinic at the Comprehensive Cancer Center (hereafter referred to as the Cancer Center). The appointment secretary called each scheduled newly-diagnosed patient and requested their participation in the study. Each patient was told that a study was being conducted to identify ways in which the Cancer Center could better understand the process of treatment for cancer patients. They also were told that they would be required to arrive at the clinic an hour earlier if they agreed to participate. If they agreed, their name was then placed on a pre-prepared list. The slots on this list had been previously assigned as either for the treatment group or the control group by random number table.

Upon arrival at the Cancer Center, the patient checked in at the reception desk. The receptionists had a list of all patients with a treatment or control group designation. Those patients were referred to the preparatory-orientation counselor of the Cancer Patient Support Program.

For patients in the control group the counselor greeted the patients and thanked them for agreeing to participate in the study, went over the consent form (see Appendix F), and asked for a signature of consent. Once consent had been obtained, the patient was given a questionnaire designed to gain background and demographic information, the protocols for the STAI Form Y, and the protocol for the Brief POMS-TMDS. All instruments were in random order to avoid an ordering effect.

For patients in the treatment group the counselor greeted the patient and invited him or her, as well as any family or friends, to join the counselor in a private counseling room. The counselor then went over the consent form and sought written consent from the patient. Once written consent was obtained, the patient and any family members or friends present received presentation of the preparatory-orientation module (see Appendix G). Based on information obtained as a result of the pilot study (Wells, 1992) it was learned that most patients come for their first visit with a family member. In order to eliminate the issue of the presence of a family member as a research variable, any patient who appeared without family or friends was eliminated from the study. Those eliminated from the study were offered access to the

preparatory/orientation module. The number of family members and their relationship to the patient also was reported.

Packets were mailed to patients three days after the first clinic visit. These packets contained the STAI, the Brief POMS-TMDS, the modified version of the Brief POMS-TMDS for the patients support person and the Oncology Clinic Questionnaire. A follow-up phone call was made 7 to 14 days after the patient's first clinic visit (see Appendix I). The primary function of the follow-up call was to assure collection of follow-up data with minimal discomfort to the patient. After completing the data gathering process, those patients in the control group were offered the opportunity to receive the preparatory/ orientation module and were told how to go about requesting it. This was offered in order to insure that all patients eventually had access to what is believed to be a beneficial program.

Independent Variable

The preparatory-orientation module consisted of three components.

1. Initially the patient and his or her family members were taken on a tour of the clinic area in the order they might routinely proceed through the clinic. This included stops at the check-in desk, vital signs, the blood collection station, a representative examination

room, the nurses' station, treatment rooms, and rest rooms. They also were shown the Cancer Patient Support Program offices and lounge area, administrative offices and a resource room. The purposes of this component of the module were a) to familiarize the patient and family with the physical layout of the clinic and with clinic routine, and b) to give the patient and family concrete sensory information about the clinic and specific information regarding treatment procedures.

2. After the tour, the patient and family returned to the counseling room and were given specific information regarding members of the health care team and their functions, clinic operations which included such things as waiting times, possible reasons for potential time changes (holidays, doctors attending conferences, etc.), information resources and support services available (the American Cancer Society, National Cancer Institute, the Cancer Patient Support Program, and their own physician), and business and insurance issues. This was delivered orally and supplemented with further examination of materials available in the resource room and a one-page information sheet (see Appendix J) that was delivered. The purposes for this component of the module were a) to provide useful information regarding the clinic and its operation, b) to provide access and information regarding available resources and support, and c) to build further

personal rapport with the patient and family.

3. Following the provision of specific information the patient and his or her family or friends were given the opportunity to ask questions or express concerns. The staff member addressed any issues with appropriate information or referrals to sources of information. Referrals to others were necessary if the answer was unknown to the staff member or if it was more appropriately answered by a member of the health care team. The purposes of this component of the module were a) to give patients and their families a chance to express any concerns or to vent feelings and to have an attentive, listening ear, and b) to provide patients and families with helpful information on dealing with their illnesses and upcoming treatment. Each participant was told to expect an additional packet of questionnaires in the mail in a few days (packets were mailed three days after the intervention) and a follow-up phone call in 7 to 14 days for a counselor to collect the results. This packet included questionnaires which sought information that could account for factors that may reduce anxiety in patients unrelated to the preparatory-orientation intervention module, and which assessed the usefulness of the preparation-orientation module (see Appendix C). In addition, the posttest administrations of the STAI, the Brief POMS-TDMS and the modified version of the brief

POMS-TMDS to be completed by the patient-identified support person were included. A cover letter accompanied each packet mailed instructing patients to complete all the questionnaires and have them handy to read to the counselor who would call soon (see Appendix L).

Questionnaires were mailed two to four days after the patient's clinic visit and were followed by a phone call in 7 to 14 days. The primary investigator made the calls without knowledge of the patients group assignment (treatment or control). The purpose of the follow-up was a) to note any continued effects of the preparatory-orientation module for at least up to two weeks after its presentation, b) to compare levels of anxiety and distress of those receiving the intervention to those in the control group for up to two weeks after its presentation, and c) to compare self- reported levels of anxiety and distress to those observed by significant others in the patients' lives.

CHAPTER IV

Results

This chapter reports the results of the analyzed data. Subject participation, hypotheses and additional data analyses will be discussed.

Subject Participation

As reported, 44 individuals who were assigned to either the treatment or control group following verbal agreement to participate in the study did not complete both assessment phases of the study. Twenty-two patients were unable to complete the initial assessment process due to medical demands (i.e., patient became ill, doctor needed to see patient immediately, or the patient became hospitalized before their scheduled clinic visit). Of these 22 patients, 13 were assigned to the treatment group and 9 to the control group. Nine patients arrived at the clinic late, cancelled their appointments, or did not show for their appointment (4 control, 5 treatment). Ten patients withdrew after arriving at the clinic, but before beginning the study (4 control, 6 treatment). One patient (control) withdrew after the initial clinic visit and two were unable to be reached for follow-up (1 control, 1 treatment). Subsequently 92 patients completed all phases of the study (48 control, 44 treatment).

Research Hypotheses

Initially, random checks of the data indicated that the scores were not normally distributed. As a result, the statistical test used for the following examination of hypotheses was the Wilcoxon Rank Sum Test which makes few assumptions about the normality of the data. This test calculates a z-statistic, and gives the probability associated with this observed z-statistic. The data analysis was completed by utilizing the SAS statistical package at the Data Management Facility of the Bowman-Gray School of Medicine.

Hypothesis One

It was proposed that newly diagnosed cancer patients presented with the preparatory/orientation module would show significantly reduced levels of state anxiety (measured by the STAI) and distress (measured by the Brief POMS-TMDS).

Results indicated that the mean STAI State-Anxiety score for treatment and control groups, respectively, were 39.2 and 42.4. While the mean score for the control group was higher, the difference was not statistically significant at the .01 level (see Table 1).

Mean scores on the Brief POMS-TMDS for treatment and control groups, respectively, were 22.1 and 22.4. The difference between the group means for the Brief POMS-TMDS was not statistically significant (see Table 1). Also

noted in Table 1 is the fact that there is no significant difference between group means for Trait-Anxiety, although this result was as expected.

Table 1

Comparison of treatment group and control group anxiety scores (STAI) and distress scores (Brief POMS-TMDS taken during initial clinic visit and at follow-up

	Initial Visit			Follow-up		
	Treatment	Control	p-value	Treatment	Control	p-value
STAI (S-Anxiety)	39.2* (12.7) 38.0 (22, 76)	42.4 (13.0) 42.5 (6, 70)	.1433	28.9 (7.2) 29.0 (17, 59)	50.1 10.8 52.5 (26, 68)	.0001**
STAI (T-Anxiety)	36.3 (11.2) 36.0 (30, 68)	38.0 (12.8) 36.5 (2, 70)	.3385			
Brief POMS-TMDS	22.1 (12.6) 30.0 (4, 62)	22.4 (11.6) 21.0 (4, 57)	.7528	12.5 (8.0) 11.0 (0, 4)	31.4 12.4 30.0 (7, 58)	.0001**

* mean
(std. dev)
median
(range)

**denotes statistically significant difference

Hypothesis Two

Hypothesis two stated that newly diagnosed patients receiving the preparatory/orientation module would demonstrate a higher level of knowledge of cancer clinic functioning and availability of resources than those in

the control group. Answers of "yes" on the Oncology Clinical Questionnaire indicated that the patient had knowledge of the subject area to which the questions referred (see Appendix C). The patients in the treatment group consistently answered more of the 20 knowledge questions "yes" than did the patients in the control group. The ratio of "yes" answers comparing treatment group to control group ranged from a low of 40 to 7 to a high of 43 to 3.

When answering "yes" patients were asked to rate how helpful was the knowledge on a Likert scale from zero (not at all) to four (very). Patients in the treatment group indicated that the knowledge represented in the questions was very important 87.47% of the time. Individual question responses of "very important" ranged from 77.36% for knowledge of the clinic phone number to 94.29% for information regarding how to manage appearance changes such as hair loss. While there were few "yes" responses by the control group, when it did occur the knowledge represented in the questions was considered very important 84.87% of the time. Individual question responses were similar to those of the treatment group. Responses of "very important" ranged from 72.21% for knowledge of when the clinic was closed and 72.45% for knowledge of the clinic phone number to 88.38% for knowledge regarding financial procedures.

Hypothesis Three

It was proposed that levels of anxiety and distress (measured by STAI State-Anxiety, and the Brief POMS-TMDS, respectively) would be significantly less for patients who had received the preparatory/ orientation module when compared to the control group in a 7 to 14 day follow-up. The group who received the intervention (treatment group) had a mean score on the STAI State-Anxiety scale of 28.9 at follow-up. The control group's mean STAI State-Anxiety score at follow-up was 50.1. The difference between these means was statistically significant (see Table 1).

Additional Findings

In addition to comparisons between control and treatment group scores, the mean scores for each group obtained during the initial clinic visit were compared to mean scores for the same group at follow-up. Mean scores on the STAI State-Anxiety for the treatment group at initiation of the study and at follow-up were 39.2 and 28.9, respectively (see Table 2). The mean scores on the Brief POMS-TMDS for the treatment group at initiation and at follow-up are 22.1 and 12.5, respectively (see Table 2). Both comparisons yield mean scores which are significantly different over time. Mean State-Anxiety scores from the STAI for the control group at initiation of the study and at follow-up were 42.4 and 50.1, respectively, yielding a statistically significant

difference (see Table 2). Similarly, the mean scores on the Brief POMS-TMDS for the control group at initiation of the study and at follow-up were significantly different (see Table 2). The Brief POMS-TMDS means for the control group at initiation of the study and follow-up are 22.4 and 31.4, respectively.

Table 2

Comparison of scores taken at initial clinic visit (Time 1) and at follow-up (Time 2) for treatment group and control group

	Treatment			Control		
	Time 1	Time 2	p-value	Time 1	Time 2	p-value
STAI (S-Anxiety)	39.2* (12.7) 38.0 (22, 76)	28.9 (7.2) 29.0 (17, 59)	.0001**	42.4 (13.0) 42.5 (6, 70)	50.1 (10.8) 52.5 (26, 68)	.0010**
Brief POMS-TMDS	22.1 (12.6) 30.0 (4, 62)	12.5 (8.0) 11.0 (0, 41)	.0001**	22.4 (11.6) 21.0 (4, 57)	31.4 (12.4) 30.0 (7, 58)	.0002**

* mean (std.dev) median (range)

**denotes statistically significant difference

The fourth research question was not directly related to the study purpose but was a question more related to confidence in the self-report results and an interest in the perception of others regarding the anxiety and distress of their loved one, who is the patient. For these reasons, this question was investigated but not raised to the level of a research hypothesis.

Results indicated that in the treatment group there was an average difference in POMS scores of -1.77 between the patient's report and the report of his or her

significant other, which is not statistically significant ($p = 0.1959$). This indicated that the family member or friend reported distress levels for the patient that were an average 1.77 points lower than the patient rated him or herself. The POMS scores may range from 0 to 40, with lower scores representing less distress.

Among those patients in the control group, there was an average difference in POMS scores of -1.30 between the patient's report and that of his or her identified support person. This difference also was not statistically significant ($p = .4232$). The difference for the treatment group but in the same direction indicating that with these patients as well, the patient's report of distress level was slightly higher than that perceived by a significant other regarding the patient.

A follow-up period of between 7 and 14 days was proposed in the methodology. Difficulties in making telephone contact with patients or patients not having completed the questionnaires when initially called resulted in follow-up of more than 14 days on occasion. For the treatment group the mean number of days between initial clinic visit and follow-up was 11.31 days (range = 7, 22). Similarly, for the control group the mean number of days between initial clinic visit and follow-up was 11.92 days (range = 7, 21).

Regression analysis of all participant scores found no significant differences in State Anxiety measures (R-Square = .3780) based on age (p = .0988), gender (p = .5340), or cancer site (p = .3097). Similarly there were no differences in other demographic variables (marital status, p = .4953; religious preference, p = .2989; years of education, p = .2924; miles traveled to the clinic, p = .7596; insurance status, p = .1417). There also were no significant differences found in POMS measures following regression analysis (R-Square = .5815) based on demographic variables (age, p = .5004; gender, p = .6536; cancer site, p = .2672; marital status, p = .3059; religious preference, p = .2511; years of education, p = .1629; miles traveled to clinic, p = .8155; insurance status, p = .2242).

Content Analysis of Question/Answer Session

As noted in the methodology section, all question and answer sessions were audio taped. The primary investigator analyzed the tapes by listening to the session and placing questions asked or concerns initiated by the patient into one of the following categories defined earlier: medical/physical, administrative/ procedural, and personal/interpersonal. There also was a category included for those patients who had no questions or concerns (see Appendix N).

The analysis of the questions and/or concerns of the treatment patients indicated that nine of the patients (21%) had no questions or concerns. Of the remaining patients, 31 (70%) asked questions or had concerns regarding medical/physical issues, 13 (30%) had concerns regarding administrative/procedural issues and 24 (55%) had concerns that related to personal or interpersonal issues.

CHAPTER V

Discussion

The purpose of this study was to examine the effect on anxiety and distress of a brief, one-time, preparatory/ orientation presentation among newly diagnosed cancer patients. This chapter will describe the conclusions proposed from the results of the study, limitations to the study and implications for future research.

Summary

Analyses of data indicated that the intervention resulted in no significant difference in anxiety or distress between the control group and the treatment group when measures were taken immediately upon arrival at the clinic for control patients and immediately after the intervention for the treatment group. Further comparisons indicated that for the control group anxiety and distress showed significant increases from the initial clinic visit to the follow-up, while the treatment group showed significant decreases in anxiety and distress over the same time period. Additionally, comparison between the control group's measures of anxiety and distress and those of the treatment group at follow-up indicated that levels of anxiety and distress are significantly lower for the treatment group.

These results are not as predicted by hypothesis one, based on findings from an earlier pilot study (Wells, 1992) which found significant differences between the two groups at the initial assessment. The pilot study had only 16 and 17 patients, respectively, in the control and treatment groups. With this relatively smaller sample, atypical scores may carry more weight and more greatly influence outcome.

Additionally, due to the clinic schedule, measures of distress and anxiety were taken prior to the patients' visit with the doctor. The anticipation of that initial meeting, which often involved specific treatment or prognostic information, certainly accounted for much of the anxiety and distress being experienced by the patient. It is not unreasonable to find that a brief, one-time intervention such as presented in this study was not powerful enough to overcome the high levels of anxiety and distress present just before seeing the doctor for the initial visit. It is, in fact, possible that answering questions concerning mood and anxiety may have resulted in heightening the patient's awareness of anxiety and distress at a time when both states were at high levels. It is clear, however, that an effect was found at follow-up. Patients in the treatment group received a printed information sheet which could have been reviewed during less hectic times after leaving the clinic.

Many of the patients in the treatment group commented during follow-up that they were impressed with the caring and concern they felt as a result of someone making the effort to ease their difficulties during the initial visit to the clinic through the preparatory/orientation module. This, and the positive interpersonal aspects of the module, were the first and perhaps the only pleasant event of their time at the clinic. As noted by Burnish et al. (1991), an associative learning process in which particular aspects of the treatment setting or procedure may become associated with aversive treatments is one explanation for anxiety or distress. Similarly, an association between the initial clinic visit and the positive aspects of the preparatory/orientation anxiety associated with return trips to the clinic, while not affecting the anxiety present before the conclusion of the initial visit.

There also is the possibility that the patient responded differently to the measurement questionnaires during the times when the questionnaires were being completed. At the initial clinic visit the patient becomes a part of a pattern that includes time spent waiting interspersed with periods of time in which many people and demands are combined as they answer questions, fill out forms and have medical procedures performed. In the midst of this situation, the patient is asked to

complete yet another group of questionnaires. This differs from the situation a week or so later when the patient receives a packet of questionnaires to complete at home at their leisure. It is possible that when given the opportunity to complete the forms at home they are more carefully read and may result in more accurate measures. The possibility also must be considered that the patient may respond as he or she thinks they are expected to based on their perception of what the study is measuring and its expected outcome.

The increase in anxiety over time found among the control group was not anticipated. This may be due to the "existential plight" described by Weisman and Worden (1976b) in which they describe the anxiety level increasing and changing over a time period that includes the first 100 days after diagnosis. The increases in anxiety and distress among patients in the control group would then simply be the natural course of events. The decreases among the treatment group would represent a successful altering of this natural pattern, for a specified time at least.

Based on responses to the Oncology Clinic Questionnaire the knowledge of clinic functioning and available support was significantly greater among patients in the treatment group. The treatment group also noted a high degree of "helpfulness" associated with this

increased knowledge. While not immediately associated with a reduction of anxiety and distress, according to the data, this increased familiarity certainly contributed to some degree to the subsequent reductions in anxiety and distress among treatment group patients.

It is clear from the content analysis of the issues raised by patients in the question and answer phase of the preparatory/orientation module that medical or treatment issues also were important. Questions in this category included inquiries regarding specific treatment procedures, side effects, duration of treatment and cure rates. Most of these questions were re-directed to the medical team. The counselor did help the patients to put these concerns into comprehensive form and reminded the patient to put the questions in writing to help them remember to ask them when seeing the doctor.

Over one-half of the patients in the treatment group had concerns that fell into the personal/interpersonal category when responding to the question and answer phase. Issues raised in this category included worries about returning to work, family reactions and issues of religion or faith. Responses to these issues involved active listening, expressions of concern and support, and reminders of the availability of support resources contained in the information sheet. This brief, interpersonal encounter between the patient and the

counselor was the aspect of the intervention most frequently mentioned by the treatment group when asked an open ended question regarding comments on their initial clinic visit (see Oncology Clinic Questionnaire, Part III, question 7, Appendix C). Patients in the treatment group mentioned talking with the counselor in a positive manner 75% of the time. The long waiting time was mentioned by 43% of the treatment group. When given the same question, 83% of the patients in the control group responded that the waiting also was too long and uncomfortable.

This study's intervention appeared to have a significant effect on the anxiety and distress of newly diagnosed cancer patients. Anxiety and distress were reduced on a somewhat delayed bases from 7 to 14 days. While not resulting in an immediate reduction in anxiety or distress the module was perceived by patients as desirable and helpful. This type of intervention can be delivered in the context of a busy outpatient clinic and can be done at a relatively small cost. In fact, the presentation of many aspects of the module could be easily carried out by trained volunteers. The importance of the interpersonal interactions involved, particularly during the question and answer portion, suggested that a trained counselor would still be necessary. Health care teams, other clinic staff as well as patients and their loved

ones should welcome any means of reducing the considerable anxiety and distress associated with a new diagnosis of cancer.

Limitations

All the conclusions and findings of this study must be viewed in light of its limitations. It was certainly a complicating factor to take post-intervention measures prior to the patient seeing his or her doctor and not having a comparison measure just after the doctor visit. While desirable, clinic procedures and respect for patients' feelings would make this measure difficult to obtain. Random assignment to treatment and control groups seems to have balanced the groups based on age, gender and cancer site. A more clear comparison may have been possible if a pre-treatment baseline had been established.

There were a number of items over which no control was exerted. The events that occurred in the lives of the patients between the initial clinic visit and follow-up were not known. Patients were asked about discussing their cancer with friends, clergy or other individuals and no significant difference was found. However, there was no way to know about books read, television programs or movies seen, or simply personal thoughts or experiences of the patient. The circumstances under which the follow-up measures were completed was uncontrolled. Once again, random assignment to conditions may have taken care of

many of these issues, however, tighter control or documentation of such variables would be an improvement.

There also exists the possibility, as noted earlier, that the taking of measures regarding anxiety and distress in the clinic setting may in fact contribute to the heightening of anxiety or distress. While empirically it may be seen that this effect would be expected to be equal between groups, and therefore, not effect experimental outcomes, it is a concern when one's ultimate purpose is to ease human suffering and provide comfort.

Implications for Future Research

Certainly of interest for any future research in this area is the difference found in measures of anxiety and distress immediately after the intervention compared to the follow-up. It would be of interest to determine how soon after the intervention the reduction in anxiety and distress begins and for how long afterwards does it continue.

Of considerable importance as well is the determination of which component or combination of components of the preparatory/orientation module were responsible for the reduction in anxiety and distress. Would the provision of information alone have been sufficient or was the interpersonal contact a crucial part of the presentation? If information was important, it would be important to determine the best delivery method.

The provision of written or videotaped information would be more cost effective if the results were the same as personal delivery of the information. It would be, therefore, a worthy goal to try and tease apart which variable or variables are most important or perhaps just as important and which variables are more amenable to change in order to provide information regarding treatment or prevention planning. A differentiation of the overall anxiety associated with hospital treatment from the anxiety specific to a diagnosis of cancer is another related research goal.

Implications for Counselor Education

This study indicated the role(s) that may be taken by professional counselors in a primarily medical setting. While not traditional counseling, a contribution to the overall well-being of the cancer patient was demonstrated by the presentation of the preparatory/orientation module. Instruction in skills specific to a medical setting and application of general counseling principles to such settings, as well as inclusion of medical sites for internships may be necessary steps taken by counselor education programs in order to make counseling students more aware of this area of practice.

Conclusion

This study has shown that it is possible to effect a reduction in anxiety and distress among patients for whom anxiety and distress is likely to be a way of life. Cancer is a group of diseases in which the pain and suffering of the illness is often challenged by the pain and suffering of the treatment. The intervention investigated herein has shown that the easing of some of the discomfort is possible at a relatively low cost in terms of money and personnel. Further examination of this subject should provide a continuing role for the counseling profession in addressing what is often considered an exclusively medical problem.

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APPENDIX A

State Trait Anxiety Inventory

APPENDIX B

Brief Profile of Mood States

APPENDIX C

Oncology Clinic Questionnaire

ID#_____

ONCOLOGY CLINIC QUESTIONNAIRE

We would like to know about your recent appointment at the Oncology Clinic at the Baptist Hospital/Bowman Gray School of Medicine Medical Center. Please answer the questions below by circling Yes (Y) or No (N). If you answer yes, please circle one number on the scale to the right to tell how helpful.

PART I

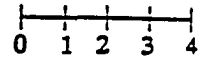
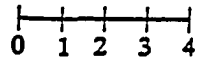
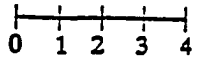
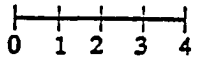
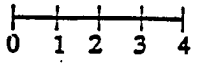
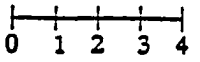
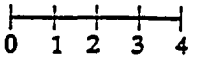
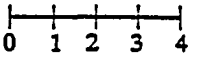
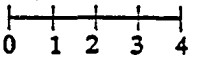
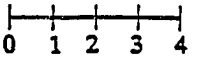
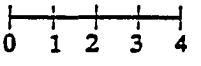
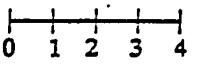
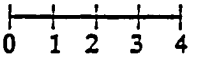
AT MY FIRST CLINIC VISIT I WAS GIVEN INFORMATION ABOUT THE FOLLOWING:

		YES NO	WAS THIS HELPFUL?
EXAMPLE: Where to park.		(Y) N	Not at all 0 1 2 3 (4) very
1.	Hours the clinic is open.	Y N	0 1 2 3 4
2.	The clinic phone number.	Y N	0 1 2 3 4
3.	How to reach someone after hours.	Y N	0 1 2 3 4
4.	Financial counseling.	Y N	0 1 2 3 4
5.	How to contact the business office.	Y N	0 1 2 3 4
6.	The Cancer Patient Support Program.	Y N	0 1 2 3 4
7.	Coping with Cancer Meetings.	Y N	0 1 2 3 4
8.	How to get support for family members.	Y N	0 1 2 3 4
9.	Support groups	Y N	0 1 2 3 4
10.	How to manage appearance changes, e.g. Hair loss, wigs, & turbans.	Y N	0 1 2 3 4
11.	How to get around the hospital.	Y N	0 1 2 3 4

		YES NO	WAS THIS HELPFUL? not at all ... very
12.	The patient resource room. (contains booklets, books, & tapes about cancer)	Y N	0 1 2 3 4
13.	Organizations that can help. e.g. The National Coalition for Cancer Survivorship	Y N	0 1 2 3 4
14.	Eating facilities in the hospital.	Y N	0 1 2 3 4
15.	A tour of the clinic.	Y N	0 1 2 3 4
16.	My health care team.	Y N	0 1 2 3 4
17.	Why I might be kept waiting.	Y N	0 1 2 3 4
18.	Why I might not see my doctor at every clinic visit.	Y N	0 1 2 3 4
19.	Writing down questions to ask the doctor.	Y N	0 1 2 3 4
20.	Important facts for new patients.	Y N	0 1 2 3 4

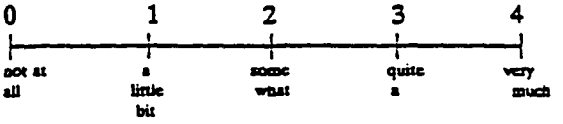
PART II.

1.	I met with a counselor at my recent clinic appointment.	Y N	0 1 2 3 4
2.	I and/or a family member met a volunteer at my recent clinic appointment.	Y N	0 1 2 3 4
3.	I have attended a support group.	Y N	0 1 2 3 4

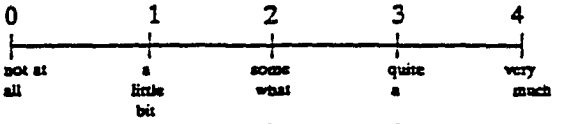
		YES NO	WAS THIS HELPFUL? not at all — very
4.	I have gotten information from the clinic resource room.	Y N	
5.	I have talked with someone about a wig/ turban.	Y N	
6.	I have discussed my cancer with:		
	a. A friend?	Y N	
	b. Another patient?	Y N	
	c. A volunteer?	Y N	
	d. Your clergyman?	Y N	
	e. A counselor?	Y N	
	f. The cancer information service?	Y N	
	g. Other _____	Y N	
7.	I have begun treatment since my first clinic visit. If yes, what type?	Y N	
	a. chemotherapy	Y N	
	b. radiation	Y N	
	c. surgery	Y N	

PART III Below is a list of statements. By circling one number per line please indicate how true each statement has been for you during the past 7 days.

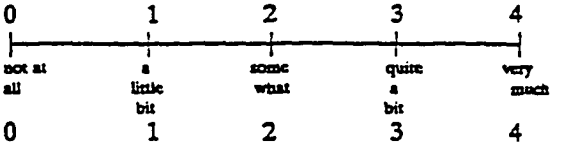
2. I have confidence in my doctor(s).



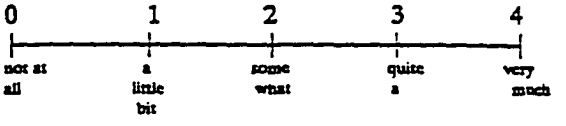
2. I am satisfied with my medical care in the clinic.



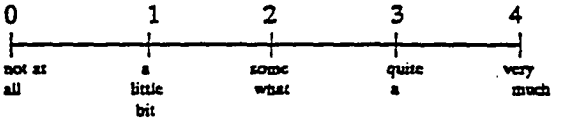
3. I am losing hope in the fight against my illness.



4. My doctor is available to answer my questions.



5. I have had a very stressful week.



6. Please indicate what has happened to make it stressful.

7. Do you have any comments about your first clinic visit?

APPENDIX D

Modified Brief POMS-TMDS

APPENDIX E

Background Information

PLEASE FILL OUT THE BACKGROUND INFORMATION REQUESTED BELOW. WHILE THIS INFORMATION WILL BE HELPFUL TO US, YOU DO NOT HAVE TO ANSWER ANY QUESTION YOU DO NOT WISH TO ANSWER. ALL OF YOUR RESPONSES WILL BE KEPT CONFIDENTIAL.

BACKGROUND INFORMATION

ID #_____

Date _____

Name_____

Address_____

_____

Phone _____
area code

Age_____ Gender _____ Male
_____ Female

Date of Birth? Month:_____ Day:_____ Year: _____

Where appropriate, please circle the number next to the answer that is correct for you.

1. What is your current marital status?

____ Married	1
____ Living as married	2
____ Widowed	3
____ Divorced	4
____ Separated	5
____ Never married	6

2. Do you consider yourself to be:

___ Asian	1
____ White, Caucasian, not of Hispanic origin	2
____ Black/African-American	3
____ Hispanic: Black	4
____ Hispanic: White	5
____ Interracial	6
____ American Indian, Native American, Alaskan Native	7
____ Other	8

SPECIFY_____

3. What are your current religious practices?

____ Attend religious services regularly (1-2 times wk) 1

____ Attend religious services periodically (1-2 times mo) 2

____ Attend religious services occasionally (1-2 times a yr) 3

4. Which of the following categories best describe the highest level of schooling you have completed?

____ No formal training 1

____ Grades 1 - 5 2

____ Grades 6 - 8 3

____ Grades 9 - 11 4

____ High school graduate 5

____ Post high school training other than college 6

____ Some college education 7

____ College or university graduate 8

____ Post college/university education 9

5. What is your current employment status?

____ Homemaker 1
occupation of the spouse:_____

____ Disabled 2
____ Currently working full time 3
____ Currently working part time 4
____ Retired 5

6. Where do you work?_____

What is your job there?_____

7. What are your current living arrangements?

____ Alone 1

____ With other adults, no children 2

____ With other adults & children 3

____ With children only 4

____ In an institution or retirement home 5

8. What is your diagnosis (type of cancer, site of cancer, etc)

_____

9. What is the date of diagnosis?_____
month date year

10. Is there any previous diagnosis of cancer in your medical history?
____ yes 1
____ no 2

If yes, what was the previous diagnosis?_____.

When was the previous diagnosis?_____.

11. What is your total annual family income?

____$0 - 4,999 1
____$5,000 - 9,999 2
____$10,000 - 19,999 3
____$20,000 - 29,999 4
____$30,000 - 39,999 5
____$40,000 - 49,999 6
____$50,000 - 59,999 7
____$60,000 - 69,999 8
____$70,000 - over 9

12. What is your health insurance status?

____Medicaid 1
____Medicare only 2
____Medicare & supplemental plan 3
____Disability insurance 4
____HMO or other limited provider 5
____Private 6
____No insurance 7
____Other 8

(specify)_____

13. Has anything happened in the past week to cause you excessive stress?

_____ Yes 1

_____ No 2

If yes, please explain what that is _____

_____

_____

14. How far did you travel today to get to the clinic?

____Less than 5 miles 1

____6-10 miles 2

____11-25 miles 3

____26-50 miles 4

____Greater than 51 miles 5

15. What person are you closest to who will be involved during your illness?_____

16. Do you give us permission to ask this person about how you are doing? Yes/No If yes sign here_____

17. We will be calling you within 7 - 14 days to learn more about your feelings. What is the best time to call?

	M	T	W	T	F	S	S
A.M							
P.M.							

What telephone number?_____

APPENDIX F

Consent Form

CONSENT FORM

I, _____, agree to participate in the study for new clinic patients at the Comprehensive Cancer Center of the Bowman Gray School of Medicine.

I understand that the purpose of this study is to learn about the feelings of cancer patients. I understand that my participation will involve the completion of several questionnaires, and may involve a short meeting. This will take approximately 40 minutes to complete. In this study, individuals will be divided into two groups randomly. Randomization is a process which is similar to the flipping of a coin. One group will follow usual clinic procedure and the other a slightly different procedure. This will in no way affect my medical care. Questionnaires will be administered on my first clinic visit and again seven to fourteen days later by mail followed by a phone call. I understand that I will receive no financial compensation for participating in this study, and that I am free to withdraw from this study at any time. Withdrawal will not influence my care. I further understand that my identity will be kept confidential. This study will be supervised by Dr. Richard P. McQuellon, Director of Psychological Services & the Cancer Patient Support Program at Bowman Gray School of Medicine. Should I have any questions concerning this study, I may contact Richard McQuellon at (919) 716-7980.

Signature_____ Date_____

Witness_____ Date_____

APPENDIX G

Procedure for Counselor Treatment Sessions

PROCEDURE FOR COUNSELOR
TREATMENT SESSION

1. Greet patient and family. Usher them into the Counseling Room or Resource Room. Clarify the purpose of the meeting is to conduct a study and to provide them with an orientation to the clinic.

2. Discuss, sign & witness consent form.

3. Tour Clinic - Specific Stops

    1. Vital Signs
    2. Blood Collection
    3. Nurses Station
    4. Chemotherapy Treatment Rooms
    5. Exam Rooms
    6. CPSP Offices
    7. Resources Room
    8. CPSP Lounge
    9. Bathrooms

4. Explain clinic operation.

    a. Here at Baptist you will have a health care team made up of doctors, nurses, physician assistants, counselors and others as necessary, so that you receive the best care possible.

    b. There may be times when you come to the clinic and will not be scheduled to see your doctor. If on one of those times, you have a concern and need to see the physician, please let the other members of your health care team and the receptionist know.

    c. There are times when there are delays of service in the clinic. Many factors cause potential delays and we ask that you try not to let that distress you. We are doing our best to see everyone promptly.

    d. It is a good idea to write down questions you have for your doctor. You'll get the most out of your time seeing the doctor if you are well prepared.

5. Give out information sheet.

   a. The Hem/Onc clinic is open Monday - Friday from 8 a.m. - 5 p.m. except for holidays. Included on this sheet are numbers for reaching the clinic during and after hours. You will be given other information for reaching your health care team as necessary. Many other resources and information numbers are included on this sheet. Those organizations and individuals stand ready and available to help. CPSP volunteers, clinic staff, and your health care team are especially good sources of information.

   b. Point out information on sheet.

   c. Respond to questions about information.

6. What questions do you have? (If question is asked that counselor cannot answer, suggest that it would be a good question for the doctor or nurse.)

7. Have patient complete background information and STAI and Brief POMS inventories. Request that forms be completed without help from family members. Offer refreshments to family members and ask if they would like to sit in lounge to wait for patient to finish.

8. After patient completes forms, thank him/her for participating and take forms for data collection. Remind patient that similar forms will arrive in the mail, and we will be calling in 7-14 days to record their responses.

9. Give patient reminder sheet.

10. Show patient where family is waiting.

APPENDIX H

Procedure for Counselor Control Sessions

PROCEDURE FOR COUNSELOR CONTROL SESSION

1. Greet patient and family. Usher them into the Counseling Room or Resource Room. Clarify that the purpose of the meeting is to conduct a study.

2. Have patient complete background information and STAI and Brief POMS inventories. Request that forms be completed without help from family members. Offer refreshments to family members and ask if they would like to sit in lounge to wait for patient to finish.

3. After patient completes forms, thank him/her for participating and take forms for data collection. Remind patient that similar forms will arrive in the mail, and we will be calling in 7-14 days to record their responses.

4. Give patient reminder sheet.

5. Show patient where family is waiting.

APPENDIX I

Procedure for Counselor Follow-Up Sessions

PROCEDURE FOR COUNSELOR
FOLLOW-UP SESSION

1. The counselor calls the patient at the time requested by the patient on the background sheet.

2. When the patient answers counselor identifies him or herself and notes that they are calling regarding the questionnaires mailed to the patient.

3. The counselor asks if the patient has time to read the questionnaire responses to the counselor. If the patient is unable to do so responses may be read by someone else. This should be noted along with the reason why.

4. The counselor will then tell the patient that he or she has the same forms as the patient and will record the patient's responses as they are read off.

5. Once all data has been collected patients in the control group will be told the following:
   "There is a program available from the Cancer Patient Support Program which will provide you with a tour of the clinic, some basic information about clinic functioning and resources available to you and will attempt to answer any questions you have. If you would like any or all of this provided for you, let the receptionist know when you check in and she will get the counselor for you."

6. Thank each patient for his or her help in the study. Tell them that a final report of the study findings will be available in the CPSP office in the clinic early this summer. They may stop by the office or call if they are interested.

APPENDIX J

Information For New Patients

INFORMATION FOR NEW PATIENTS

HOSPITAL

o THE HEMATOLOGY/ONCOLOGY CLINIC
Open 8:00 a.m. - 5:00 p.m.
Monday - Friday
except holidays
Phone (8 a.m. - 5 p.m.) 716-4354
Phone after hours - 716-2001, ask for Oncology Fellow on Call

o Social Services Department 716-3513

HOSPITAL BUSINESS

o Insurance Information/Business Office
Inpatient 716-3222
Outpatient 716-3310

o Financial Counseling 716-4705

CANCER PATIENT SUPPORT PROGRAM
716-3741 OR 716-7980

The Cancer Patient Support Program provides a variety of services to help patients and family members. These include:

- Coping With Cancer - A two session meeting with one of our counselors to discuss ways of coping with diagnosis and treatment. Call 716-3741 for more information.
- Support for Family - A one session meeting with one of our counselors to discuss how family members can help the patients and themselves. Call 716-3741 for more information.
- Support Groups
  - "Coping With Cancer" - Thursday, 11:00 a.m., CPSP lounge, Hematology/Oncology Clinic, 7th floor, Clinical Sciences Building.
  - "Learning Together" - A series of informational programs held in the CPSP lounge, Hem/Onc Clinic, e.g. Coping With Chemotherapy Side Effects CALL 716-3741 or 716-7980 for times and dates.

- Appearance Consultation - (Hair care information and special programs, i.e., the Look Good...Feel Better Program.) See CPSP Staff or call 716-3741 for dates and times.

- Directions around the hospital - Ask a CPSP volunteer or contact a CPSP staff member in the Hem/Onc Clinic or call 716-3741 or 716-7980 for further assistance.

- Resource Room - The CPSP media room is across the hall from the CPSP lounge. It is:

  - A collection of informative pamphlets and books for your keeping that are of interest to patients and family members.

  - A lending library of books that are of interest to patients and their families.

  - A lending library of video tapes that are of interest to cancer patients and family members.

OTHER ORGANIZATIONS

- Cancer Information Services of the National Cancer Institute 1-800-422-6237 or 1-800-4-CANCER

- Y-ME Hot Line (For breast cancer) 1-800-221-2141

- Leukemia Society of America 1-800-955-4LSA

- National Coalition for Cancer Survivorship
  323 Eighth Street, SW
  Albuquerque, New Mexico 87102
  1-505-764-9956

- American Cancer Society, Inc. To get the number of the chapter near you call 1-800-227-2345.

  - ACS CHAPTER IN
    Greensboro 273-2102
    Forsyth County 768-1224
    High Point 884-1449

- Anderson Support Network 1-800-345-6324 - If you would like to talk with a patient with a similar diagnosis, they will place you in contact with the patient as soon as possible.

ADDITIONAL INFORMATION

Clinic routine varies depending on the reasons for the appointment. Usual clinic procedure starts with a check-in at the reception desk. After checking in, patients and those with them are asked to sit in the waiting room or the CPSP lounge. Patients will be called over the loudspeakers to vital signs for weight, temperature, and blood pressure and for to blood collection if necessary. Sometimes exam rooms are available immediately and if patients are to see the Dr., they are escorted to exam rooms without returning to the waiting room. Other times, patients waiting to see the physician will return to the waiting room and will be called when exam rooms become available. Either way, a family member or other may join the patient in the exam room, if the patient wishes.

Some visits to the clinic may be for treatment only, with no Dr.'s appointment. In that case, after vitals and/or bloodwork is completed, patients will return to the waiting room or CPSP lounge to be called to the nurses station.

There may be times when patients are not scheduled to see the Dr. If on one of those times, patients have a concern or need to see the physician, please let reception and other members of the health team know.

Although those in the clinic do their best to prevent delays, many factors may cause delays to happen. We in the clinic ask that patients try not to let delays distress them. We are doing our best to see everyone promptly.

Upon completion of most clinic visits, patients check out at the check out area near the front reception desk before leaving the clinic.

EATING FACILITIES WITHIN THE HOSPITAL

- Cafeteria - 7 days per week, 6:30 a.m. - 9:00 a.m., 11:00 a.m. - 2:00 p.m., 5:00 p.m. - 7:00 p.m. - Take the elevator in the Clinical Sciences Building down to M. Enter the main section of the hospital and follow the signs to the cafeteria.

- Penthouse Cafeteria - Monday thru Friday 8:00 a.m. - 10 a.m., 11:00 a.m. - 2:00 a.m. - Take the elevator in the Clinical Sciences Building down to G. Enter the main section of the hospital and follow the signs to the Reynolds Tower elevators. Take the Reynolds Tower elevators to PH. Cafeteria is visible

as one steps off elevator.

- Deli - Monday thru Friday 6:30 a.m. - 4:30 p.m. - Take the elevator in the clinical sciences building down to G. Enter the main section of the hospital and follow the signs to Watlington Hall. Pizza parlor & deli will be on the left side of the hallway.

- Pizza Parlor and Vending - Pizza Parlor open Monday thru Friday, 11:00 a.m. - 7:00 p.m. - Vending open 24 hours a day, 7 days per week. Directions are the same as to the Deli.

APPENDIX K

Thank You/Reminder Sheet

REMINDER SHEET

Thank you for taking part in our study today. Your participation is helping us to better serve you and the other patients we see in our clinic. We appreciate your time and interest.

In several days you will receive some forms by mail similar to those you filled out today. Please place them near your phone. Our interviewer will be calling in 7-14 days to record your answers.

Thank you again for your help.

APPENDIX L

Cover Letter

WAKE FOREST
UNIVERSITY

The Bowman Gray
School of Medicine

Department of Medicine
Section on Hematology/Oncology

Dear

Thank you for taking part in our study on your recent visit to the Oncology Clinic at Bowman Gray/North Carolina Baptist Hospital Medical Center. Your participation is helping us to better serve you and the other patients we see in our clinic.

Enclosed please find some forms that are similar to the ones you filled out in the clinic. Please fill them out and have them near the phone. Our interviewer will call you in the next several days.

If you have any questions or have not heard from us in the next week, please call Dr. Richard McQuellon at 919-716-7980.

Thank you again for your participation in this study.

Sincerely,

Richard P. McQuellon, Ph. D.
Director, Psychological Services &
Cancer Patient Support Program

RPM/se

Medical Center Boulevard, Winston-Salem, North Carolina 27157
TELEX 806449 TELEFAX (919) 716-4204

APPENDIX M

Flow Chart

FLOW CHART

TREATMENT	CONTROL
1. Patient presents to reception.	1. Patient presents to reception.
2. Reception notifies counselor on call.	2. Reception notifies counselor on call.
3. Counselor greets patient and gets consent form signed.	3. Counselor meets with patient to complete forms. a. consent b. background c. questionnaire
4. Counselor gives tour and discusses information with patient.	4. Counselor gives patient thank you/reminder forms.
5. Counselor asks patient to complete background information and to alert counselor upon completion.	5. Patient returns to waiting area for vitals, blood, appointment.
6. Counselor instructs patient to complete forms and answers any questions.	6. Patient sees doctor.
7. Counselor gives patient thank you/reminder forms.	7. Patient checks out.
8. Patient returns to waiting area for vitals, blood appointment.	
9. Patient sees doctor.	
10. Patient checks out.	

APPENDIX N

Content Analysis of Question/Answer Session

Content Analysis of Question/Answer Session

Place a hash mark in the appropriate column for each question or concern raised by the identified treatment patient.

Patient#	No question or concerns	Medical-Physical	Administrative-Procedural	Personal-Interpersonal	Other